

Low-grade non-Hodgkin lymphoma

Including:

Follicular lymphoma

Mantle cell lymphoma

Marginal zone lymphomas

Waldenström's macroglobulinaemia



This book has been researched and written by Lymphoma Action, the only UK charity dedicated to people affected by lymphoma.

We would like to thank our incredible supporters whose generous donations enable us to offer our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.

To make a donation towards our work, please visit [lymphoma-action.org.uk/Donate](https://www.lymphoma-action.org.uk/Donate)

Your lymphoma type, stage and date of diagnosis



Your treatment plan

Key contact

Name: _____

Role: _____

Contact details: _____

Job title/role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist (CNS) or key worker	
Emergency hospital number	

About this book

Over 14,000 people are diagnosed with non-Hodgkin lymphoma each year in the UK. This book explains what low-grade non-Hodgkin lymphoma is, how it is diagnosed, and some of the treatment options that might be available to you.

We have information on the more common types in this book, and information about other types at lymphoma-action.org.uk/Types

You might also be interested in our book: *Living with and beyond lymphoma*, which gives tips on coping practically, physically and emotionally. See page 151 for other resources you might find helpful.

This book is split into chapters. You can read just the sections that are relevant to you at any given time.

Words that are in **bold orange** are explained in the glossary on page 142.

If you would like a copy of this book in large print, please contact us (page 150).

Contents

● What is low-grade non-Hodgkin lymphoma?	7
● Symptoms	21
● Tests, diagnosis and staging	29
● Planning treatment	51
● Treatment options	67
● After treatment	109
● Types of low-grade non-Hodgkin lymphoma	131
● Glossary, help, support and more information	142



“ I was diagnosed with lymphoma, a type of cancer. The nurse took me into a private room with my sister and I told her I hadn't even heard of lymphoma. She explained more about it, but in truth a lot of it didn't sink in at the time.

Cornita, diagnosed with low-grade non-Hodgkin lymphoma

What is low-grade non-Hodgkin lymphoma?

What is lymphoma?	8
How lymphoma develops	11
Types of lymphoma	12
Who gets non-Hodgkin lymphoma?	15
Possible causes	15
What is the outlook?	17

What is lymphoma?

Lymphoma is a type of blood cancer. It develops when **white blood cells** called **lymphocytes** grow out of control.

Lymphocytes are part of your **immune system**, which helps to fight infection. Lymphocytes travel around your body in your **lymphatic system**, surrounded by a fluid called lymph. The lymph fluid passes through glands (**lymph nodes**), which are found throughout your body. For this reason, lymphoma is sometimes known as a cancer of the immune system.

If you have lymphoma, your lymphocytes divide in an abnormal way or do not die when they should. The abnormal lymphocytes build up and are usually noticed in lymph nodes in your armpits, neck or groin. However, they can collect in almost any part of your body.



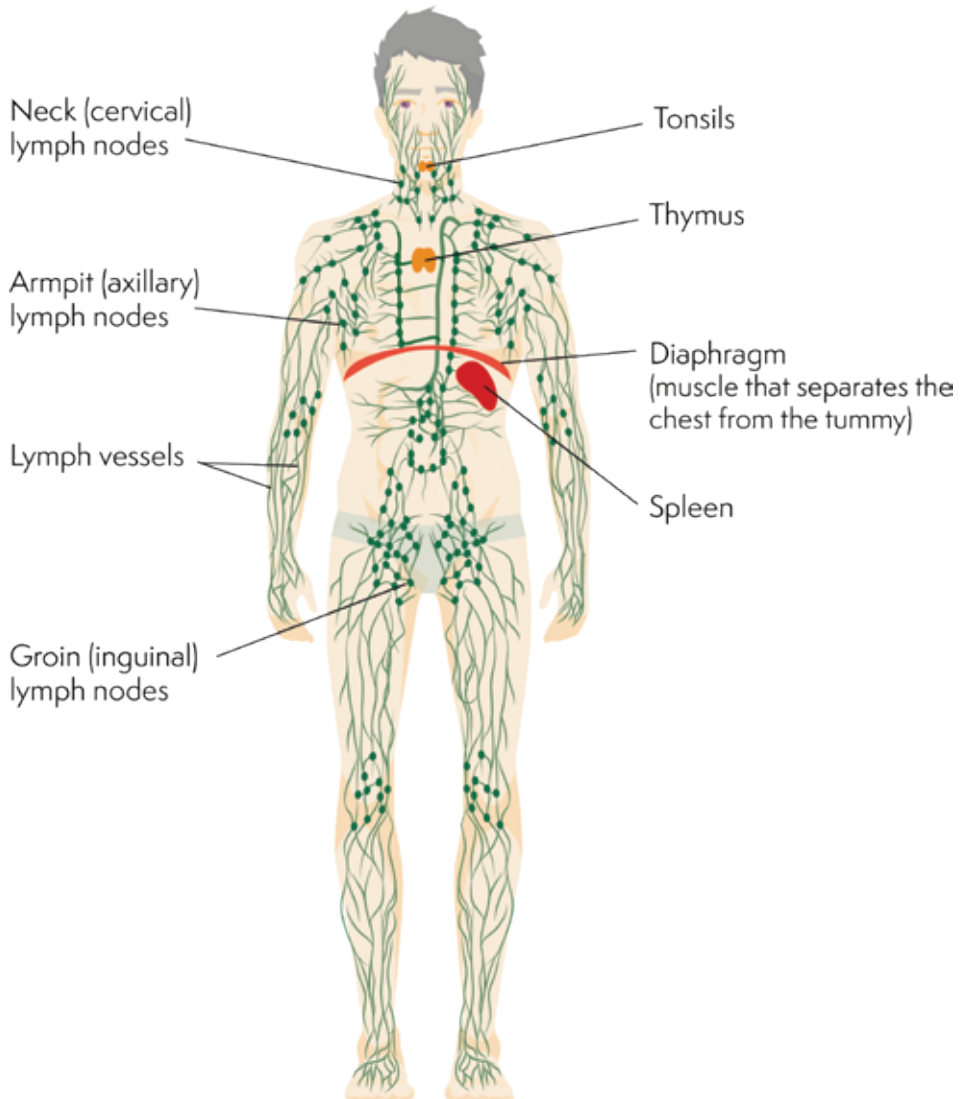
Search 'what is lymphoma?' on our website for more information and to watch a short animation about it.

The lymphatic system

Your **lymphatic system** is part of your immune system. It runs throughout your body carrying lymph fluid. It is a network of tubes (lymph vessels) and lymph nodes (sometimes known as lymph glands). It also includes organs, such as your **spleen** (which filters blood) and **thymus** (where some of your immune cells develop).

The lymphatic system has some key functions. It:

- filters out germs (bacteria, viruses and parasites) and poisons (toxins)
- helps to destroy cells that are old, damaged or abnormal
- keeps a healthy balance of lymph by draining it from your tissues and returning it to your bloodstream
- absorbs fats and vitamins from your digestive system and puts them into your bloodstream.



The lymphatic system

How lymphoma develops

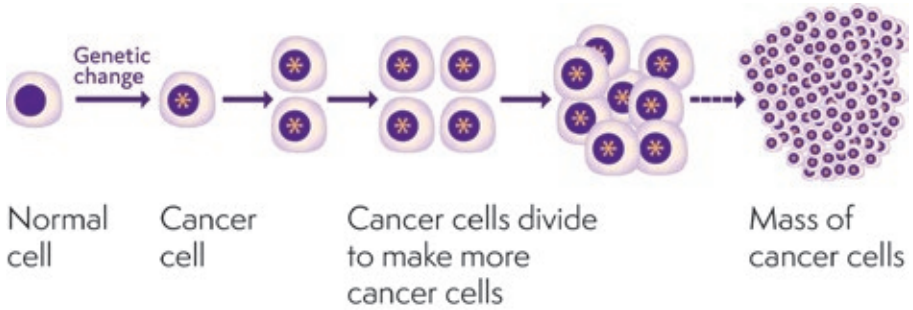
Your body is made up of cells. Some of these cells divide throughout your life. They replace old cells that die off naturally.

Usually, chemical control signals keep cell division and cell death in careful balance. This makes sure that you only make the number of new cells your body needs.

Throughout life, changes (mutations) happen to our DNA (genetic material). Most of the time, these mutations are harmless, but they can sometimes cause disruption. This can lead to abnormal cells that stop responding to the control signals. These cells then might:

- start dividing when they shouldn't
- carry on dividing when they should stop
- stay alive when they should die.

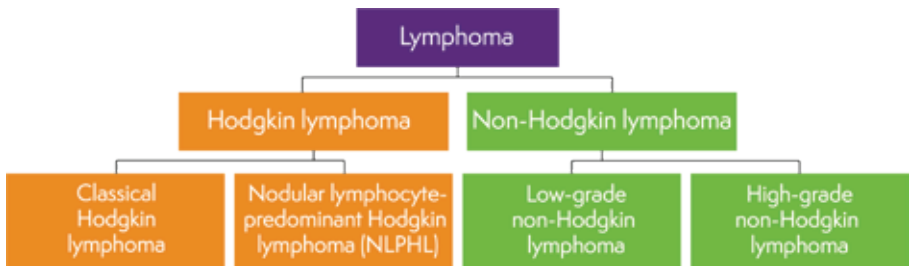
When this happens, it can lead to a build-up of abnormal cells (cancer). It usually takes a number of different mutations for a cancer to develop. With lymphoma, the abnormal cells build up and usually collect in a lymph node. However, they can collect in other parts of the body, such as the spleen, liver or **bone marrow**.



How cancer develops

Types of lymphoma

There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphoma and non-Hodgkin lymphomas.



The main types of lymphoma

Non-Hodgkin lymphomas are grouped based on:

- how fast the lymphoma cells are growing
- the type of lymphocyte they developed from.

Low-grade or high-grade non-Hodgkin lymphoma

Lymphoma cells can grow slowly or quickly.

- Non-Hodgkin lymphomas that grow slowly are called **low-grade** (or indolent) non-Hodgkin lymphomas.
- Non-Hodgkin lymphomas that grow quickly are called **high-grade** (or aggressive) non-Hodgkin lymphomas.

This book focusses on low grade non-Hodgkin lymphoma. We also have a *High-grade non-Hodgkin lymphoma* book. Visit lymphoma-action.org.uk/Shop to order your free copy.

B-cell or T-cell lymphoma

There are two main types of **lymphocyte** in your immune system: B lymphocytes (B cells) and T lymphocytes (T cells). In healthy people, they protect your body from infection and illness.

- T cells recognise and target germs (especially viruses) or cancer cells. They either kill the cell directly, or activate other parts of your immune system to kill it.
- B cells make **antibodies** that stick to specific **proteins** on the surface of cells that don't belong in your body, such as viruses, bacteria or cancer cells. The antibodies can either kill the cell directly, or act like a flag that attracts other immune cells to destroy it.

Either of these types of lymphocyte can grow out of control and cause lymphoma to develop.

- Non-Hodgkin lymphomas that develop from B cells are called B-cell lymphomas.
- Non-Hodgkin lymphomas that develop from T cells are called T-cell lymphomas. T-cell lymphomas are less common.

There are many types of lymphoma in each of these main groups. Each type behaves differently and might need different treatment.

In this book we cover the more common types of **low-grade B-cell non-Hodgkin lymphomas**:

- Follicular lymphoma
- Mantle cell lymphoma
- Marginal zone lymphomas
- Waldenström's macroglobulinaemia.

Ask your clinical team if you're not sure what type of lymphoma you have.



Further information about the different types of low-grade non-Hodgkin lymphoma, including those not included in this book, can be found on our website. Search 'low-grade non-Hodgkin lymphoma' to find out more.

Who gets non-Hodgkin lymphoma?

Around 14,200 people are diagnosed with non-Hodgkin lymphoma each year in the UK – around 38 people every day.

Non-Hodgkin lymphoma can affect:

- any age group including children and young people, although in the UK, most people diagnosed are over 55
- people of any ethnicity
- both males and females, although it is slightly more common in males.

We produce a *Young person's guide to lymphoma* for people aged between 15 and 24. Visit lymphoma-action.org.uk/Shop to order your free copy.

Possible causes of non-Hodgkin lymphoma

In most cases, the cause of lymphoma is not known. It's likely that lots of different factors have a part in its development.

Unlike many other types of cancer, lifestyle factors don't have much impact on your risk of developing lymphoma. It is not infectious so you can't catch lymphoma from anyone or pass it onto anyone else.

On the next page we outline some of the things that can increase your chance of developing lymphoma (risk factors).

Genetics

While anyone can develop lymphoma, if you have a close relative (such as a parent or sibling) who has lymphoma, you have a **very slightly** higher risk of developing it compared to the average person.

Problems with your immune system

Lymphoma is more common in people who have a condition that weakens their immune system, such as human immunodeficiency virus (**HIV**). Lymphoma is also more common in people who are taking medicines that dampen their immune system (immunosuppressants). However, most people who have these conditions do **not** develop lymphoma.

Infection

Some infections can increase your chance of developing lymphoma. Certain viral and bacterial infections have been linked with specific lymphoma types – see pages 136 to 139 for more information.

Many of the infections linked to lymphoma are very common. Most people who have these infections do **not** get lymphoma. Scientists don't know why some people who have certain infections get lymphoma while most don't.



If you'd like to learn more about some of the possible causes and risk factors of lymphoma, search 'causes' on our website.

What is the outlook for people with low-grade non-Hodgkin lymphoma?

The outlook for people with non-Hodgkin lymphoma depends on the specific lymphoma type as well as many individual factors.

Low-grade non-Hodgkin lymphomas generally respond well to treatment but they are hard to get rid of completely. They are usually treated with the aim of controlling the lymphoma rather than curing it.

Low-grade non-Hodgkin lymphomas can often be controlled for many years. People might go for long periods when they feel well and don't need treatment. Over time, though, low-grade non-Hodgkin lymphomas usually come back and need more treatment. Most people have several different treatments over the course of their illness.

It helps some people to think of low-grade non-Hodgkin lymphoma as a long-term (chronic) illness that needs treatment from time-to-time.

See page 60 for more information on low-grade non-Hodgkin lymphoma that doesn't respond to treatment or comes back after remission.



“ *I slowly came to terms with the fact that I am facing a condition that is manageable but not curable. It has taken some time to adjust to this new life; my new normal. A life that includes regular hospital checks, blood tests and treatment.*

Nicola, diagnosed with follicular lymphoma

Your lymphoma specialist is the best person to talk to about the likely outcome of your treatment. In giving you this information, they consider a range of factors, including:

- your age
- the exact type of lymphoma you have
- how much lymphoma you have in your body and where it is (the **stage** of your lymphoma – see page 43)
- the results of your tests and scans (page 30)
- your general health and fitness.

Summary

- Lymphoma is a type of blood cancer.
- Lymphoma develops when white blood cells called lymphocytes grow out of control.
- There are over 60 different types of lymphoma. They are broadly grouped into Hodgkin lymphoma or non-Hodgkin lymphoma.
- Low-grade non-Hodgkin lymphoma is a slow-growing type of lymphoma.
- It is more common in older people.
- Doctors don't know exactly what causes it.
- Low-grade non-Hodgkin lymphoma is usually treated with the aim of controlling or managing the lymphoma, rather than curing it.



“ *I was in Italy skiing. It had been a really enjoyable holiday, but when I got back I started to have several symptoms. I felt really tired, I started to lose weight without trying, was experiencing night sweats and in addition I developed a persistent cough. To add to all this, I was then experiencing really bad back and neck pain.*

Nigel, diagnosed with low-grade non-Hodgkin lymphoma

Symptoms of low-grade non-Hodgkin lymphoma

About symptoms of low-grade non-Hodgkin lymphoma	22
Common symptoms	23
Extranodal symptoms	27

About symptoms of low-grade non-Hodgkin lymphoma

Low-grade non-Hodgkin lymphoma can cause a range of symptoms depending on which part of your body is affected. Most people have a mixture of symptoms. Even people with the same type of lymphoma can have different symptoms.

People with low-grade non-Hodgkin lymphoma often have mild symptoms. Some people might not have any symptoms at all and be diagnosed during tests for something else.

Speak to your clinical team for advice to help you manage any symptoms you are experiencing.



You can find tips to help you cope with symptoms of lymphoma on our website (search 'coping with symptoms') and in our book: *Living with and beyond lymphoma*.

Common symptoms

The more common symptoms of lymphoma are outlined in this section. However, it's important to note that these can have other causes. Having one or more doesn't necessarily mean that you have lymphoma.

Swollen lymph nodes



A common symptom of low-grade non-Hodgkin lymphoma is a swollen lump or lumps that don't go down after a couple of weeks.

These swollen **lymph nodes** are not usually painful and have a 'rubbery' texture.

Swollen lymph nodes often develop in places you can feel them, such as in the neck, the armpit or groin. Sometimes they may develop deep inside your body where you can't feel them. Swollen lymph nodes can form large lumps.

It is important to remember that lymph nodes can swell for lots of reasons (for example, if you have an infection). Most people with swollen lymph nodes do not have lymphoma.

Fever



Fever is a high temperature (above 38°C /100.4°F). Fever is almost always caused by an infection, but there are a few other less common causes, including lymphoma. With lymphoma, fevers are usually mild and come and go.

Drenching sweats



Lymphoma can cause sweats that make your nightclothes and bedsheets soaking wet. They are often described as 'drenching'. They most commonly occur at night but can sometimes happen during the day.

Unexplained weight loss



Unexplained weight loss means losing significant weight quickly without trying to.

Your doctor might say you have '**B symptoms**' if you have one or more of the following symptoms: fever, drenching sweats or unexplained weight loss.

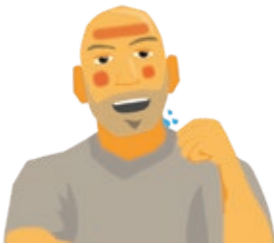
Fatigue



Fatigue is exhaustion that can be physical, emotional or mental. Sometimes people describe fatigue as feeling 'drained'. You might feel tired doing very little.

Most people who have cancer get fatigue at some point. This can be a symptom or a side effect of treatment (page 95). However, lots of factors can contribute to fatigue, including other medical conditions, heightened stress and anxiety.

Difficulty recovering from infections



Lymphoma can weaken your immune system. Usually, **white blood cells** fight infections. However, if you have lymphoma, you have some cancerous white blood cells, which can make it harder to fight infections. The infections you get could be more frequent, more severe, or last longer than they would if you didn't have lymphoma.

You'll find more on page 99 about signs and symptoms of infection, and when to seek medical attention.

See page 102 for tips to help lower your risk of infection.

Itching



Itching is not a very common symptom in low-grade lymphoma but may occur. It can be worse at night and in hot weather.

Poor appetite



You might not feel like eating much, or you might feel full after eating only a small amount.

Extranodal symptoms

Sometimes, non-Hodgkin lymphoma starts in an organ in your body rather than a lymph node. For example, it might develop in the liver, gut, lung, skin, **bone marrow** or brain. This is called '**extranodal**' lymphoma. The symptoms you might get depend on where the lymphoma is.

Symptoms of extranodal lymphoma can include:

- unexplained pain
- indigestion, diarrhoea, constipation or bloating
- a persistent cough or breathlessness
- a rash
- a tendency to bruise or bleed easily
- headaches, memory issues, drowsiness or confusion.

Summary

- Non-Hodgkin lymphoma can cause different symptoms depending on where it develops.
- People with low-grade non-Hodgkin lymphoma often have mild symptoms, or no symptoms at all.
- The most common symptom of non-Hodgkin lymphoma is a swollen lymph node or nodes, often in the neck, armpit or groin.
- Your clinical team consider many factors when planning your treatment, including whether or not you have B symptoms (fever, drenching sweats and unexplained weight loss).



“ A blood test showed poor kidney function that needed further investigation. An initial biopsy taken from the area was inconclusive, but my clinical team told me that they suspected lymphoma. Around three weeks later, a further biopsy confirmed that I had follicular lymphoma and that I would need to start treatment with chemotherapy.

Ahilan, diagnosed with follicular lymphoma

Tests, diagnosis and staging

Diagnosis of non-Hodgkin lymphoma	30
Blood tests	31
Lymph node biopsy	32
Scans and X-rays	35
Bone marrow biopsy	41
Test results	43
Staging of non-Hodgkin lymphoma	43

Diagnosis of non-Hodgkin lymphoma

Your GP is likely to be the first person you speak to about any symptoms or health concerns.

Your GP will ask you to tell them about your symptoms and check for any swollen (enlarged) **lymph nodes**. This information alone can't tell them whether or not you have lymphoma – you'll need to have tests and scans for them to find out more. Usually, you first have simple blood tests.

You'll be referred to a hospital specialist and seen quickly if your GP thinks there is a possibility that you might have lymphoma.

Once you are referred to a hospital specialist, you're likely to need further tests and scans. It's very important that the health professionals within your clinical team get all the information they need so that they can plan the most suitable treatment for you.

We outline some of the most common tests and scans for lymphoma in this section. You might not need all of them, but in most cases you will need a **biopsy** (page 32) to confirm a diagnosis of lymphoma.

Most people have these tests as an outpatient, but some people may need to stay in hospital if they have become unwell.

You can find out more on adapting to a diagnosis of lymphoma in our book *Living with and beyond lymphoma*.



For more information about tests and scans, visit lymphoma-action.org.uk/Tests

Blood tests

You will have blood tests as part of a diagnosis for lymphoma. Blood tests can help doctors see how the lymphoma is affecting your body, and to plan the best treatment for you.

Blood tests can also help to check:

- **Your general health.** For example, a ‘full blood count’ measures your levels of different types of cells: **red blood cells**, **white blood cells** and **platelets**. Lymphoma and its treatment can lower your levels of these cells. This can cause problems that might need treatment. You might also need to take some extra health and safety precautions.
- **Whether it’s safe for you to have treatment.** If your blood counts are low, your doctors might advise waiting until they are higher before it is safe for you to have treatment.
- **For signs of inflammation.** This can be a sign of infection and might need treatment.

- **How well your kidneys, liver and thyroid gland are working.** Sometimes, lymphoma and its treatment can affect the functioning of these organs.
- **Your recovery from treatment.** This can include checking for any signs of **late effects** (health problems that develop months or years after treatment – page 120).

For most blood tests, you don't need to do anything to prepare. For some blood tests, you might need to fast (not eat or drink anything except water) or stop taking particular medications for a certain amount of time before your test. Your clinical team should tell you if you need to do this.

A doctor, nurse or phlebotomist (someone trained to take blood) takes the sample. The whole process only takes a few minutes.

Lymph node biopsy

Most people need a lymph node **biopsy** to confirm whether or not they have lymphoma.

A lymph node biopsy is a minor procedure where a sample of cells is taken from a swollen lymph node for examination in a laboratory.

The type of biopsy you have depends on where the swollen lymph node is and how close it is to the surface.

- A **core needle biopsy** takes a very small sample of a lymph node. This type of biopsy is the most common and is also known as a 'core biopsy' or a

'needle biopsy'. In most cases you'll be given a local anaesthetic so that you do not feel the needle going in. In some cases you might be offered pain relief and a sedative to help you relax.

- A **laparoscopic (keyhole) biopsy** removes all or part of a lymph node. This type of biopsy is given under general anaesthetic.
- An **excisional biopsy** removes a whole lymph node.
- An **incisional biopsy** removes a small part of a lymph node.

Speak to a member of your clinical team if you feel worried about the procedure.

Your wound is covered with a protective dressing. Before you leave the hospital, you should be given clear guidance about how to care for the biopsied area. This is to help prevent infection and to stop the dressing from coming loose.

You can usually go home on the same day as having a biopsy, but check with your doctor in advance.

If you require sedation, the general advice is for someone to collect you and drive you home. Speak to a member of your clinical team for help organising transport if this is difficult for you to arrange.

It is important to contact your clinical team straightaway if you have any problems with the wound or notice any signs of infection. This includes bleeding, swelling, discharge from the biopsied area, fever (a temperature above 38°C/100.4°F), chills and sweating.

Ask your doctor how long it will be before you get the results of your biopsy. Usually results come through within 10 days to 2 weeks but they can take longer.

Occasionally, the first biopsy does not give enough information to make a diagnosis and you might need to have another biopsy, but your doctor will talk to you about this.



Listen to our podcast where Consultant Haematopathologist, Dr Bridget Wilkins, answers some of the most commonly asked questions about biopsies and diagnosis of lymphoma. You can hear it on our website, on Apple podcasts or on Spotify. Search 'biopsy podcast' at lymphoma-action.org.uk

Scans and X-rays

Different types of scans are helpful for different things.

They might be used to:

- diagnose and **stage** lymphoma
- help doctors find the best place to take a biopsy sample from
- plan your treatment
- check your response to treatment
- check for any signs of **relapse**.

Usually, you have a scan at your local hospital as an outpatient. If your local hospital doesn't have the right scanning machine for you, you might have to travel to another hospital. Sometimes it's possible to have a scan at a mobile unit.

Scans aren't painful, but you might find it uncomfortable if you have to lie still for a long time – it might be up to an hour. Speak to a member of your clinical team if you feel anxious about this or about any aspect of having a scan. You might find it helps to talk through what to expect. In some cases, you might be offered a sedative – but talk to them about this in advance of the day, to see whether it's suitable for you and to give them time to arrange it.

PET/CT scans

Positron-emission tomography (PET) scans and computed tomography (CT) scans are among the most common scans doctors use for people affected by lymphoma. Often, they're done in the same appointment as a **PET/CT scan**.

A PET/CT scan can help give a clear picture of which areas of your body are affected by lymphoma.



CT scanner

Photo credit: Tyler Olson/Shutterstock.com

PET uses a harmless radioactive sugar to look at the level of activity of cells in your body. Cells that are more active, such as lymphoma cells, take up more sugar than less active cells. A special camera detects the radioactivity and these show up as 'hot spots' on the scan image.

CT scans use lots of X-rays to take pictures through your body. They're better than regular X-rays at taking pictures of the organs inside your body, including **lymph nodes**.

You will be given advice, usually from the radiology department, to help to prepare you for your scan.

This might include:

- not eating or drinking (known as 'fasting') for a few hours before the scan
- having a special dye (**contrast agent**) as an injection before your scan – this helps to show up certain parts of your body more clearly on the scan image
- guidance about if and when to take any medication you usually take – for example, medicine for diabetes
- not doing strenuous physical activity in the 24 hours before your scan.

Staff will ask you to remove any metal you're wearing and ask whether you could be pregnant.

Some scans use very low levels of radiation. You will not be radioactive after a CT scan. However, with a PET/CT scan, you will give off very low levels of radiation for around 6 hours afterwards. As a precaution, you should avoid close contact with pregnant women, babies and very young children during this time. Drinking plenty of fluids after the scan will help to flush your system.



Find out more about PET/CT scans on our website, including answers to frequently asked questions. Search 'PET/CT' at lymphoma-action.org.uk

Ultrasound scans

Ultrasound scans use high-energy soundwaves to take pictures of the inside of your body. These soundwaves bounce off tissues and organs inside your body, making echoes. The echoes are recorded and can be used to help build up a picture.

You might have an ultrasound scan to:

- examine lymph nodes that are near the surface of your skin
- look at your **spleen**
- help your doctor find the best place to take a **biopsy**.

You'll be given information about how to prepare for your ultrasound scan, including whether to have a full or an empty bladder for the scan. You might also be asked not to eat anything for a few hours beforehand.

X-rays

X-rays use high-energy waves, similar to radio waves. These take pictures through your body and build an image on a computer screen.

You might have an X-ray to check:

- for swollen **lymph nodes** inside your chest
- the position of a central line (central venous catheter, page 71) if you need one for **chemotherapy** (page 68)
- your risk of fracture if the lymphoma has weakened your bones.

You need to sit, stand, or lie still to have an X-ray. It does not hurt and only takes a few minutes.

MRI scans

Magnetic resonance imaging (MRI) scans use strong magnets to take pictures of the inside of your body.

You might have an MRI scan if you:

- are allergic to the **contrast agents** used in CT scans
- have suspected lymphoma cells in your **central nervous system** or **CNS** (brain and spinal cord)
- are pregnant, to avoid radiation.

You'll need to take off any metal that you're wearing before your scan.

For the scan, you lie on a bed that moves into a tube, and you need to lie very still for up to an hour. The MRI machine is very noisy – you should be offered earplugs and might be able to listen to music.



Photo credit: iStock.com/Hispanolistic

MRI scanner

Tell your clinical team if you:

- have any metal in your body, including a pacemaker, hip replacement, implantable defibrillators, ear (cochlear) implants, staples from surgery and metal clips and plates put in after an injury. Your doctors will find out more about the type of metals in your body and decide on whether it's safe for you to have an MRI scan.
- feel worried about being in an enclosed space (claustrophobic) so that they can help you to manage this. In some cases, you might be offered an anti-anxiety drug before the scan.

Bone marrow biopsy

Bone marrow is the spongy tissue in the middle of your larger bones. It is where blood cells are made.

A bone marrow biopsy checks whether you have lymphoma in your bone marrow.

Very often, a PET/CT scan (page 36) is effective in checking for lymphoma in your bone marrow. However, low-grade lymphoma can be difficult to see from scans, and you might have a bone marrow biopsy.

A bone marrow biopsy sample is usually taken from your hip bone (pelvis). The procedure can be uncomfortable, you can be given medication to help you relax.

- You have a local **anaesthetic** to numb the area where the biopsy is being taken.
- A biopsy needle is inserted into the middle of the bone to collect the sample. Often two needles are used, one to collect some liquid bone marrow, and the second to get a small solid sample.
- The needles are removed and a dressing put over the area.
- The whole procedure usually takes 10 to 15 minutes.

When you are given the appointment, remind your clinical team if you are taking any blood thinning medication, as this may need adjustment for the procedure.

A bone marrow biopsy is a safe procedure. However, you should contact your clinical team if you develop any of the following:

- fever (temperature above 38°C/100.4°F)
- pain where the sample was taken that gets worse or that lasts more than a few days
- redness or swelling where the needle went into your skin
- bleeding that doesn't stop when you put pressure on it.

These could be signs of infection or a complication that needs prompt medical attention.

Test results

Your clinical team gather as much information as possible from the tests and scans you have had. You will then have an appointment to discuss the results of the tests. You can ask to take a family member or a friend to be with you if you would like to. This can be helpful to offer support, help remember the information and to ask questions.

Many people feel anxious while waiting for tests results. You can ask your doctor for an idea of how long you'll need to wait for your results.



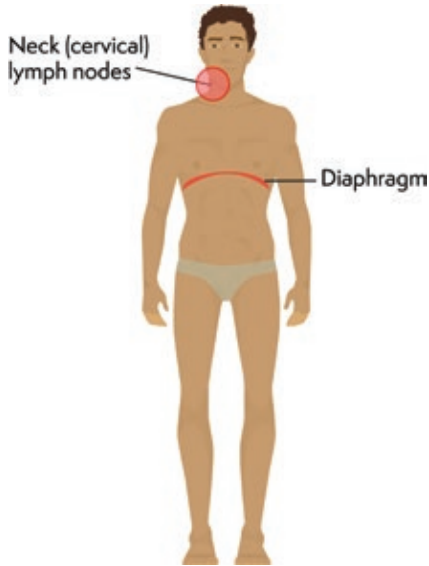
Visit lymphoma-action.org.uk/Waiting for tips on how to cope with waiting for test results and to watch a video explaining why they can take a while.

Staging of non-Hodgkin lymphoma

'Staging' is the process of working out which parts of your body are affected by lymphoma (how 'advanced' your lymphoma is). The results of your tests and scans help doctors to work out the **stage** of your lymphoma.

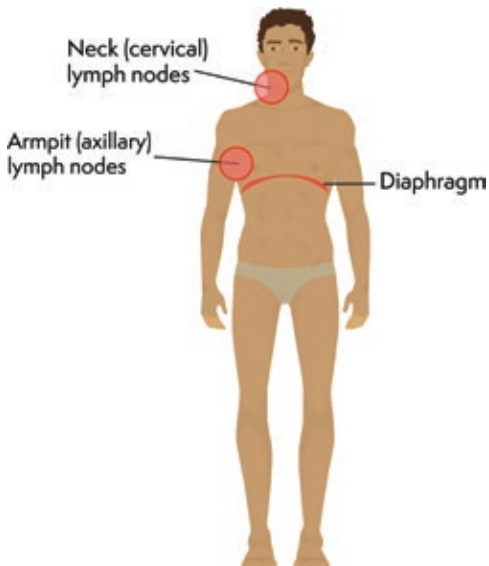
Staging is important because it helps your clinical team plan the most appropriate treatment for you.

There are four main stages of non-Hodgkin lymphoma. These are sometimes written in Roman numerals (I, II, III and IV).



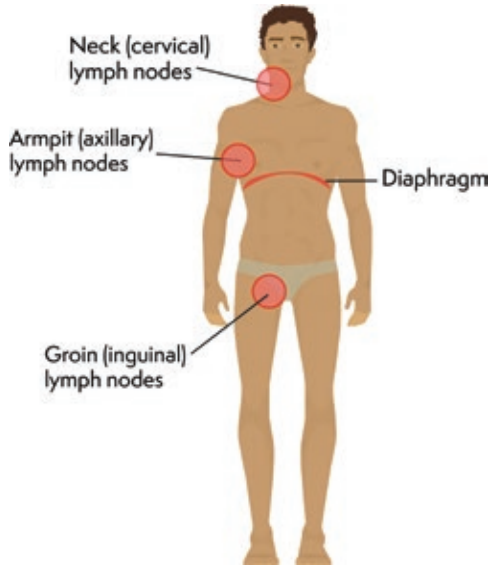
Stage 1

Lymphoma is in only one group of lymph nodes (gland). This could be anywhere in your body.



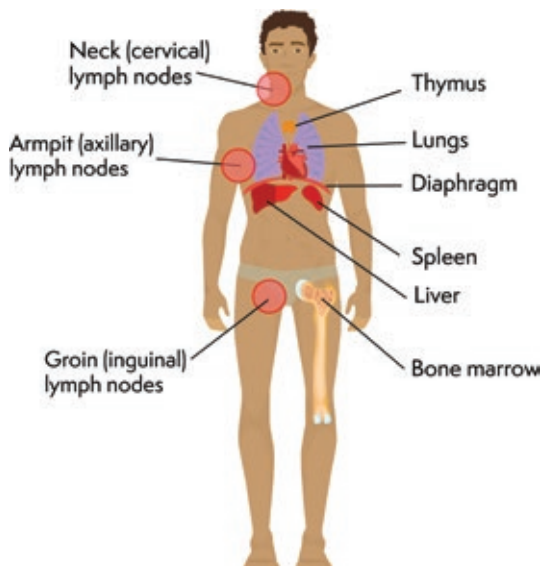
Stage 2

Lymphoma is in two or more groups of lymph nodes. These could be anywhere in your body, but all on the same side of your diaphragm*.



Stage 3

Lymphoma is in lymph nodes on both sides of your diaphragm*.



Stage 4

Lymphoma has spread from the lymph nodes to an organ outside of the lymphatic system (for example, to the liver, lungs, bone marrow or solid bones)

* The diaphragm is the muscle separating your chest from your tummy.

You might also have letters after your stage.

A	You don't have any B symptoms .
B	You have one or more B symptoms (weight loss, night sweats or fevers).
E	Extranodal lymphoma means that the lymphoma affects an area outside the lymphatic system .
S	Lymphoma is in the spleen (part of the lymphatic system).
X	One or more of your affected lymph nodes is considered to be large or 'bulky' (bulky disease). Not all hospitals use the letter 'X'.

As an example, if your lymphoma is stage 3B you have lymphoma in lymph nodes on both sides of your diaphragm, and you have at least one B symptom (weight loss, night sweats or fevers).

Early stage and advanced stage lymphoma

Your clinical team might talk about 'early' stage or 'advanced' stage non-Hodgkin lymphoma.

- 'Early' stage means either stage 1 or stage 2 lymphoma.
- 'Advanced' stage generally means either stage 3 or stage 4 lymphoma.

Your lymphatic system runs throughout your body, so, quite often, non-Hodgkin lymphoma is advanced when it is diagnosed.

Unlike many other cancers, advanced stage non-Hodgkin lymphoma can be successfully treated.

Grading of follicular lymphoma

If you have follicular lymphoma (page 133), your doctor might tell you the grade (1, 2, 3A or 3B) as well as the stage of your lymphoma. The grade relates to the number of large **lymphocytes** that the pathologist can see under a microscope. Grade 1 has the fewest and grade 3B has the most. Grades 1 and 2 are often grouped together and referred to as 'grade 1 to 2' follicular lymphoma.

Grades 1 to 2 and 3A follicular lymphoma are all slow-growing and are treated in the same way. The grade does not affect the likely outcome of treatment.

Grade 3B follicular lymphoma is usually fast-growing. Under a microscope, it looks like a type of high-grade non-Hodgkin lymphoma called diffuse large B-cell lymphoma (DLBCL). It is treated like a high-grade non-Hodgkin lymphoma.

We produce a separate book about high-grade non-Hodgkin lymphoma. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a copy.

Summary

- Low-grade non-Hodgkin lymphoma is usually diagnosed using a lymph node biopsy.
- You might have other tests such as blood tests, CT scan or PET/CT scan to find out which parts of your body are affected by lymphoma.
- The results of your tests and scans help your doctor plan the most suitable treatment for you.
- Speak to a member of your clinical team if you have questions about any tests you're having, or if you feel worried about having them.
- Your clinical team can give you an idea of how long it will be before your test results are available.



Notes



“ After being diagnosed at the age of 44, I was put on active monitoring (watch and wait) which lasted for 6 years. Once symptoms developed, it was decided that I should start chemotherapy, which gave me partial remission for a couple of years. I then started a targeted treatment which really kept my WM under control. I feel very privileged to now be part of a clinical drug trial which is working really well and allowing me to get on with my life.

Sandra, diagnosed with Waldenström's macroglobulinaemia

Planning treatment

Treatment aims	52
Your clinical team	52
Planning your treatment	56
Active monitoring	57
Starting treatment	59
If lymphoma comes back or doesn't respond to treatment	60

Treatment aims

Low-grade non-Hodgkin lymphoma is usually treated with the aim of controlling the lymphoma rather than curing it. Low-grade non-Hodgkin lymphomas can often be controlled for many years. People might go for long periods when they feel well and don't need treatment.

However, over time, low-grade non-Hodgkin lymphomas usually come back and need more treatment. Most people have several different treatments over the course of their illness.

It helps some people to think of low-grade non-Hodgkin lymphoma as a long-term (chronic) illness that needs treatment from time-to-time.

Your clinical team

Your treatment is planned by a **multidisciplinary team (MDT)** made up of different professionals, sometimes from more than one hospital, including specialists. They each have knowledge and expertise in different specialist areas, to help offer you the best care. The team meets to discuss and plan your treatment, taking into account your individual needs, general health and preferences. Their decisions are also guided by national treatment guidelines.

The person who has overall responsibility for your care is likely to be a consultant haematologist or a consultant oncologist.

Your key worker

You should have a key worker who you can contact with any questions or concerns you might have about your lymphoma or treatment, including how it affects your day-to-day life.

Usually, your key worker is your lymphoma or haematology clinical nurse specialist (CNS).

“ *As a clinical nurse specialist, I'm there from the point of diagnosis, through treatment and beyond. I help people affected by lymphoma to understand what's happening, answer questions, and support with any treatment-related and emotional difficulties.*

*Barbara von Barsewisch,
Haematology Clinical Nurse Specialist*

You should be given the name and contact details of your key worker – if you're not given this information, ask your lymphoma consultant for it. You can write the contact details of your key worker on page 3 of this book.

Your key worker is often the member of your clinical team who helps you to identify and manage any issues that arise from living with lymphoma. This includes any needs that are practical, financial, physical, emotional and social. To help with this, they sometimes use a questionnaire. You might hear this referred to as a Holistic Needs Assessment or 'HNA'.

We have more information about day-to-day living on our website and in our book *Living with and beyond lymphoma*.

If you are aged up to 25 years old

While most people who are diagnosed with non-Hodgkin lymphoma are over 55, it can affect people of any age.

Children and young people with non-Hodgkin lymphoma are treated in a specialist children's cancer centre called a Principal Treatment Centre (PTC). There are 21 PTCs across the UK, so your nearest might be some distance from your home.

It might be possible to have some treatment at a hospital closer to home through a children's community nursing team. Having some appointments at the PTC and some at a local hospital is known as 'joint care' or 'shared care'.

Teenagers and young people aged 16 to 25 have an additional teenage and young adult multi-disciplinary team (TYA MDT). This team consists of health and social care professionals who specialise in treating young people with cancer. It can also include professionals such as youth support workers, who organise fun and relaxing activities on the hospital ward.



Find out more about lymphoma in children and young people on our website.

You can download or order a copy of our *Young person's guide to lymphoma* at lymphoma-action.org.uk/Books

Planning your treatment

Your treatment is planned according to your individual needs. Sometimes, people with the same type of low-grade non-Hodgkin lymphoma have different treatments.

When working out your treatment plan, your **MDT** takes into account:

- which type of lymphoma you have (page 131)
- the **stage** of your lymphoma (page 43)
- your age
- any symptoms you are experiencing
- any other health conditions you have
- your general physical fitness
- the possible side effects of treatment (page 95)
- the possible long-term or **late effects** of treatment (page 120)
- your feelings and preferences about treatment options
- any other factors that might be important to you in the future, such as having a family.

To help work out the best treatment plan for you, you might need to have more tests to check how well your heart, lungs, liver and kidneys are working.

If you don't have symptoms, your clinical team might not recommend treatment straightaway. Instead, you might be closely monitored (this is known as **active monitoring**).

Active monitoring (watch and wait)

For some types of low-grade non-Hodgkin lymphoma, there is no benefit in having treatment if the lymphoma is not causing problems. Instead, you have regular check-ups to monitor how the lymphoma is affecting you. This is called **active monitoring** (also known as active surveillance or watch and wait).

Active monitoring does **not** mean there is no suitable treatment for you. It means that, while you are well, you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it, but this might not be for months or years. You might never need treatment.

Treatment is just as effective if it is saved until it is needed.

We produce a separate book on active monitoring for lymphoma. Phone 0808 808 5555 or visit lymphoma-action.org.uk/Books to order a free copy.

Your clinical team might suggest active monitoring if:

- your lymphoma is not causing troublesome symptoms
- your lymphoma is not growing quickly
- your blood tests don't show any significant problems
- your lymphoma is not affecting any of your major organs (such as your heart, lungs or kidneys).

You might have active monitoring when you are first diagnosed with lymphoma, or after a course of treatment that has shrunk your lymphoma but has not got rid of it completely.

When you are on active monitoring, you have regular check-ups with your doctor, clinical nurse specialist or another member of your clinical team to make sure your lymphoma doesn't need treatment. They talk to you about how you're feeling and whether you've noticed any change in your symptoms or any new symptoms. They might also examine you and take blood tests. If necessary, you might have a scan but this isn't routinely done unless you have new symptoms.

If you notice a change in symptoms, feel unwell or have concerns about your health, contact your clinical team straightaway. Don't wait for your next appointment.

You might end active monitoring and start treatment if:

- your symptoms become difficult to cope with
- you develop **B symptoms**
- your lymphoma starts to grow quickly
- your test results suggest that your lymphoma is affecting the functioning of your organs or your **bone marrow**.

Starting treatment

Your clinical team plan your treatment specifically for you. They take lots of factors into account to give you the best possible care.

In the next chapter, we outline some of the common treatments for low-grade non-Hodgkin lymphoma:

- chemotherapy – page 68 combined with antibody therapy – page 77; this is called ‘chemo-immunotherapy’
- targeted therapy – page 76
- radiotherapy – page 82
- high dose chemotherapy with stem cell transplant – page 87
- being part of a clinical trial – page 92.

It’s unlikely that you will have **all** of these treatments, so you might just want to read the sections that are relevant to you. Pages 133 to 140 give details on treatment options for specific lymphoma types.

It can be difficult to weigh up the benefits and risks of the possible treatment options. Talk it through with your clinical team and, if you would like to, your family and friends. Ask as many questions as you need to help you make a decision.

Once you have a confirmed diagnosis and treatment plan it is important to consider any long term implications. Dependent on your age you may wish to discuss fertility. Fertility preservation should be arranged before your treatment starts, so it's a good idea to talk to your clinical team about your fertility early. If you are a parent of a child with lymphoma, speak to your child's clinical team before his or her treatment begins.

If you can, visit your dentist before you start treatment for lymphoma as you might not be able to have dental work done during or soon after treatment.

Once you start your treatment, you might have a CT scan or a PET/CT scan (page 36) to check how well you are responding to it. Your consultant uses the results of the scan to guide them in planning the rest of your treatment.

If lymphoma comes back or doesn't respond to treatment

Low-grade lymphoma usually responds well to treatment. However, at some point, it is likely to come back. This is known as **relapsed lymphoma**. It might not happen for many years.

Occasionally, lymphoma doesn't respond well to the first choice of treatment. This is called **refractory lymphoma**.

It is usually treated in a similar way to relapsed lymphoma.

Having relapsed or refractory lymphoma can be very distressing, but many people are successfully treated again.

If your lymphoma relapses, you are likely to be the first person to notice. It might come back where it was before or it might affect a different part of your body. You might have the same symptoms as before or different symptoms.

If you're worried that your lymphoma has relapsed, contact your clinical team straightaway.

If your clinical team thinks your lymphoma might have relapsed, you have tests and scans to confirm it and help your team decide on the most appropriate treatment for you.

Transformation

Occasionally, low-grade lymphoma changes (transforms) into a faster-growing type of lymphoma.

If your clinical team thinks your lymphoma might have transformed, you are likely to have a **biopsy** to check for faster-growing cells. Transformed low-grade lymphoma is usually treated like high-grade lymphoma (page 13).

We have a separate book on high-grade non-Hodgkin lymphoma. Visit lymphoma-action.org.uk/Books or phone 0808 808 5555 to download or order a copy free of charge.

Coping with the fear of relapse

It is natural to feel anxious about the possibility of your lymphoma relapsing. Whenever you feel ill, you might worry it's the lymphoma again. It can be difficult to get the right balance between monitoring your health and worrying unnecessarily over minor symptoms.

Everyone copes with the fear of relapse in their own way. It can help to talk about your concerns with your clinical team, your family and friends, or with other people affected by lymphoma.

Tips for coping with the fear of relapse

- Ask your clinical team what signs of relapse to look out for.
- Talk to family, friends or other people affected by lymphoma.
- Consider talking through your fears with a professional, for example a counsellor.
- Try to stay active and do things you enjoy.

Our Helpline Services team (page 150) offer emotional support if you'd like to talk about your concerns. They can also put you in touch with our Buddy service.

How is relapsed or refractory low-grade non-Hodgkin lymphoma treated?

If your lymphoma doesn't respond to treatment or comes back after treatment, it can be very upsetting. However, there are several treatment options that can be successful.

The treatment you have depends on:

- how the lymphoma is affecting you
- the type of treatment you've already had and how your lymphoma responded to it
- the treatment options that are available for your type of lymphoma
- how well you coped with the treatment
- how quickly your lymphoma came back
- your age
- how fit you are.

Your clinical team might discuss several different treatment options with you. Low-grade lymphoma grows slowly and you don't usually need to start treatment urgently.

Treatment options include:

- active monitoring – page 57
- chemotherapy – page 68 combined with antibody therapy – page 77; this is called ‘chemo-immunotherapy’
- radiotherapy – page 82
- targeted therapy – page 76
- high dose chemotherapy with stem cell transplant – page 87
- CAR-T cell therapy – page 90
- being part of a clinical trial – page 92

The treatment options available are different for each lymphoma type, see pages 133 to 140 for information specific to your lymphoma type.

What happens if lymphoma relapses again?

Many people with low-grade non-Hodgkin lymphoma relapse more than once. You are likely to receive a number of different treatments over the course of your lymphoma, which aim to keep it under control.

The treatment options for low-grade non-Hodgkin lymphoma that has relapsed again are similar to those used for first relapse. If you relapse several times in a short space of time, your clinical team might recommend a more intensive approach.

If your lymphoma comes back repeatedly, your treatment options are more limited because it is unlikely that treatment you’ve had before will be beneficial. Together,

you and your clinical team may decide whether to continue with treatment or whether to concentrate on your quality of life. There are lots of palliative care options to control your symptoms and to keep you well (and out of hospital) for as long as possible.

Summary

- Low-grade non-Hodgkin lymphoma is usually treated with the aim of controlling the lymphoma rather than curing it.
- A 'multidisciplinary team' of health professionals is involved in your care. You should have a named key worker, who is your main contact.
- Your treatment is tailored to you, based on your test results and your individual circumstances.
- If your lymphoma isn't causing serious health problems, you might not need treatment straightaway.
- Your clinical team plan your treatment specifically for you, there are many treatment options available.
- Refractory lymphoma is lymphoma that does not respond to your first treatment. Relapsed lymphoma is lymphoma that responds to treatment but then comes back.
- Most types of low-grade non-Hodgkin lymphoma relapse at some point, but it might not be for many years.
- There are several treatment options for relapsed or refractory low-grade non-Hodgkin lymphoma.



“ *For my second batch of chemotherapy I was given rituximab and bendamustine which thankfully was again successful, with fewer side effects. The experience did not seem as harsh as the previous chemotherapy and I was particularly relieved that the anti-sickness drugs given to me seem to have improved enormously. I am now back on active monitoring (watch and wait).*

Alan, diagnosed with B-cell non-Hodgkin lymphoma

Treatment options

Chemotherapy	68
Targeted treatments	76
Radiotherapy	82
High dose chemotherapy with stem cell transplant	87
CAR-T cell therapy	90
Clinical trials	92
Maintenance therapy	94
Side-effects of treatment	95

Chemotherapy

Chemotherapy is treatment with drugs. It works in one or both of the following ways:

- stopping lymphoma cells from dividing, so that they die off
- triggering lymphoma cells to die.

Lymphoma cells are very responsive to the effects of chemotherapy, which is why it is often the most suitable treatment.

Unfortunately, chemotherapy also affects some of your healthy cells, particularly the ones that divide rapidly. This includes blood cells, hair follicles, skin cells, and the lining of the mouth and gut. This is the cause of some of the common side effects of chemotherapy (page 95).



Watch our short animation video that explains how chemotherapy works. Search 'chemotherapy animation' on our website.

Before chemotherapy

You will have blood tests to check that your blood counts (red cells, white cells and platelets) are at a level that is considered to be safe for you to have treatment.

If your blood counts are low, your clinical team might advise waiting for a little while (sometimes just a few days) before having treatment, until they are high enough. You might also be given treatment to help boost your blood cell counts (page 105).

Having chemotherapy

You usually have chemotherapy for low-grade non-Hodgkin lymphoma as an outpatient in a day case unit or chemotherapy unit. You go to the hospital on treatment days and can go home afterwards.

If you are having more intensive chemotherapy, you might have to stay in hospital for your treatment. Even if you are not having intensive therapy, you might need to stay in hospital for your first treatment to make sure you don't develop any serious problems such as **tumour lysis syndrome**.

Chemotherapy cycles

You usually have chemotherapy as a number of treatments or '**cycles**'. After each cycle of treatment, you have a rest period, to allow your body to recover. During each cycle, you might have to go to hospital once, or on a number of days. This depends on the exact chemotherapy you have.

Chemotherapy is given in cycles because many drugs work best on cells that are in the process of dividing. Having your chemotherapy in a number of treatments at different times increases the chances of it affecting all lymphoma cells.

In between your treatment days, you usually have lots of medicines to take at home. Some of these might be part of your chemotherapy treatment plan (**chemotherapy regimen**). Other medicines are to help control any side effects of treatment (see page 103).

Intravenous (IV) chemotherapy

Most chemotherapy is given intravenously (as a drip or injection into a vein).

Your nurse can inject some chemotherapy drugs over a minute or two. Other drugs have to be given more slowly through a drip (infusion). This could take anywhere from 30 minutes to a number of hours, depending on the drugs you have.

Tell your nurse if you feel any discomfort when you are having IV chemotherapy. They can check that the drugs are going in properly and make any adjustments they need to.

IV drugs are given through a cannula or a central venous catheter.

Cannula

A cannula is a tiny, soft plastic tube that is inserted into a vein (usually in your arm) by a small needle. It is removed after each treatment. You have a new one put in each time you go for treatment.

Central venous catheter ('line')

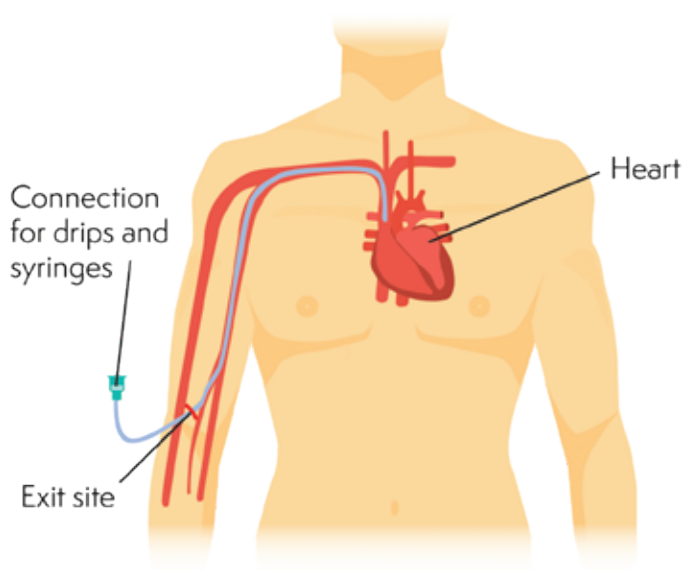
A central venous catheter (or central line) is a longer plastic tube that goes into a larger vein near your heart. A central line usually stays in for all of your treatment.

A line can also be used to:

- give you drugs and other fluids
- take blood samples for blood tests more easily
- save you the discomfort of repeated needle pricks.

There are different types of line:

- **PICC line** (peripherally inserted central catheter), which goes in through a vein in your arm, above the bend of your elbow. It is held securely in place by a dressing.
- **Tunnelled central line**, which is usually positioned on your upper chest. Part of it runs in a 'tunnel' under your skin. Examples include a Hickman® line and a Groshong® line.
- **Totally implantable line**, which is a thin, soft tube that runs under the skin before going into a vein in your chest. It can be used to deliver long-term chemotherapy while lowering the risk of infection. An example is a 'port-a-cath'.



A PICC line

Lines are put in during a small operation done under local or general **anaesthetic**. Once it's in place, a line isn't usually painful. However, if you feel any discomfort, tell a member of your clinical team.

Once it's fitted, your line is covered with a simple dressing to protect it. You will be given instructions on how to care for it once you go home. This includes how to take baths and showers while it is in place and how often you need to attend the hospital to have the dressing changed.

Lines can sometimes become infected. Occasionally, a blood clot can develop around them. Contact your hospital immediately if you develop any symptoms of infection, including:

- redness or heat around the area (site) of the line
- a high temperature (above 38°C/100.4°F)
- swelling in your arm.

Oral chemotherapy

You might have some or all of your chemotherapy by mouth (orally) as a tablet or capsule. You should be given guidance about how to store and take any chemotherapy drugs that you're given to take at home. If you are not told how to deal with these, ask your clinical nurse specialist or another member of your clinical team.

Unless you've been told to by a member of your clinical team, do not crush or open the tablets or capsules. If you have a dossette box from your local chemist for medication that your GP prescribes, the chemist cannot add the chemotherapy tablets to the dossette box.

It is important that other people don't handle your chemotherapy drugs. If you are helping someone to take chemotherapy, wear protective gloves when handling the drugs.

Your chemotherapy treatment plan

Chemotherapy drugs for lymphoma are often given as a treatment plan that includes more than one type of drug – this is known as a **chemotherapy regimen**. You have these drugs all at once so that the different drugs can work on different phases of the cell cycle. Having them together helps to kill as many lymphoma cells as possible.



Find out more about chemotherapy, including answers to frequently asked questions, on our website. Search 'chemotherapy.'

Common chemotherapy regimens for low-grade non-Hodgkin lymphoma

Your treatment is planned specifically for you. The most common chemotherapy drugs and regimens for low-grade non-Hodgkin lymphoma are:

- **CVP** – made up of cyclophosphamide, vincristine and prednisolone
- bendamustine
- **CHOP** – made up of cyclophosphamide, doxorubicin (or hydroxydaunorubicin), vincristine (**Oncovin**[®]) and prednisolone
- chlorambucil
- cytarabine.

In most cases, chemotherapy is given alongside an **antibody therapy** (a type of **targeted treatment**, page 76). This is called **chemo-immunotherapy**.

Search 'chemotherapy drugs' at [macmillan.org.uk](https://www.macmillan.org.uk) to find out more about particular chemotherapy drugs or regimens.

Safety precautions while you are on chemotherapy

Your clinical team will give you guidance about any safety precautions you should take while you are having chemotherapy.

- **Infection:** Take steps to lower your risk of infection. Be aware of the possible signs and symptoms of infection and who to contact if you notice any (page 99).
- **Sex:** While you are on chemotherapy treatment, use a barrier method, such as a condom, to avoid passing chemotherapy to your partner during vaginal, anal or oral sex. This also protects you against infection, as well as acting as contraception to avoid conceiving a child.

Talk to your clinical team if you want to have a baby. People who have had lymphoma are usually advised to wait for up to 2 years after finishing treatment before trying to start a family.

Targeted treatment

Targeted treatments are medicines that have been specially designed to attack particular **proteins** on lymphoma cells. These proteins are more common in lymphoma cells than in healthy cells and are often important in helping the cancer cells grow and survive.

Clinical trials are researching lots of different targeted therapies, some of which are, or might soon be, available to treat lymphoma.



Search 'targeted treatments' on our website to find out more about specific targeted treatments for people with lymphoma.

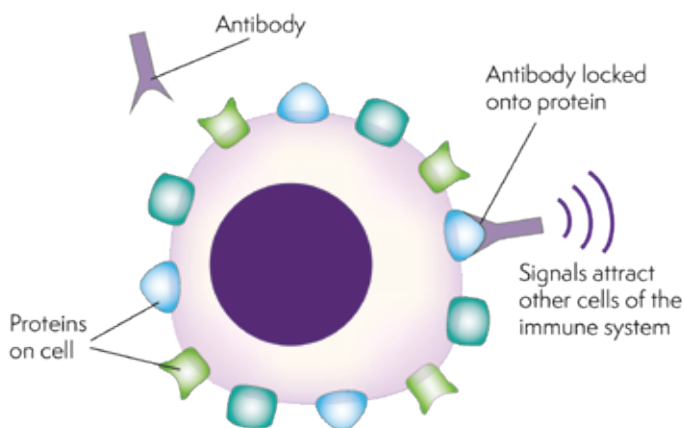
Antibody therapy

Antibody therapy is a type of targeted treatment.

Your **lymphocytes** make antibodies. These antibodies recognise and stick to particular proteins on the surface of cells that don't belong in your body (foreign cells), such as viruses or bacteria. They then either kill the foreign cell or help your **immune system** find and destroy it.

Antibody therapy uses antibodies that have been made in a laboratory to target cancer cells.

Antibody therapy works through your immune system. This is why it is also known as 'immunotherapy'.



Antibody therapy: antibodies stick to particular proteins on lymphoma cells

The most commonly used antibody therapy to treat non-Hodgkin lymphoma is called rituximab. Obinutuzumab is another antibody treatment which may be used to treat follicular lymphoma. Rituximab and obinutuzumab target a protein called CD20 on the surface of B cells.

You might have antibody therapy on its own, or alongside chemotherapy. This is called **chemo-immunotherapy**.

When rituximab is given with chemotherapy, the regimen name includes 'R' for rituximab, for example R-CHOP. When obinutuzumab is given with chemotherapy, the regimen name is similarly changed to include 'O' (or sometimes 'G' because of the trade name Gazyvaro®).

- If you are having rituximab with chemotherapy, you have it on the first day of each treatment **cycle**.
- If you are having obinutuzumab with chemotherapy, you have it on day 1, day 8 and day 15 of your first treatment cycle. After this, you have it on the first day of each treatment cycle.
- If you are having rituximab on its own, you usually have it once a week for 4 to 8 weeks.

Before you have antibody therapy, you have medicines such as antihistamines and **steroids** to help prevent any reactions to it. You then have the antibody therapy through a drip into a vein. You have your first dose slowly. It will take a few hours. You have the rest of your doses more quickly unless you have serious side effects the first time. If you are having

rituximab, you might have it as an injection under your skin (subcutaneously) after the first dose.

The most common reactions to antibody therapy are shivers, fevers and flu-like symptoms. This is called an 'infusion reaction'. It is more likely to happen with your first dose, which is why you have it more slowly.

Some people have an allergic reaction to antibody therapy. If this happens, you are monitored in hospital for a while. You might need to have antibody therapy more slowly in the future, or stop the treatment altogether.

Side effects of rituximab vary from person to person. If you experience any side effects, speak to a member of your clinical team. They can slow down the treatment to reduce the side effects and give you advice on how to manage them.

Other targeted treatments

There are lots of different types of targeted treatment. They work in different ways depending on the proteins they attack.

Examples of targeted treatments available to treat low-grade non-Hodgkin lymphoma are listed here. Some are only currently available to treat specific lymphoma types or to treat lymphoma that has come back or has not responded to initial treatment.

Bortezomib

Bortezomib (sometimes known by its tradename Velcade®) stops proteins inside cells from being broken down. This can stop lymphoma cells working properly and they therefore die.

You might have bortezomib if you have mantle cell lymphoma (page 134) that has not been treated before and you're not able to have a **stem cell transplant**.

You usually have bortezomib combined with rituximab, cyclophosphamide, doxorubicin and prednisone (known as VR-CAP). You have it as an injection into a vein (intravenously) or just under your skin (subcutaneously) twice a week for 2 weeks followed by a 10 day rest period. You have six to eight **cycles** of treatment.

Ibrutinib

Ibrutinib blocks a protein called 'BTK' on the surface of B cells. This can make lymphoma cells die or stop them dividing.

You might be offered ibrutinib if you have relapsed or refractory mantle cell lymphoma (page 134).

You take ibrutinib as an oral tablet once a day. You carry on taking it unless your lymphoma stops responding or you develop troublesome side effects.

Lenalidomide

Lenalidomide is a targeted therapy that helps your **immune system** attack lymphoma cells and stop them growing.

You might be offered lenalidomide, in combination with rituximab, if you have relapsed or refractory follicular lymphoma (page 133). This combination is sometimes called R², after rituximab and Revlimid[®] (the brand name for lenalidomide).

You take lenalidomide as oral capsules once a day for the first 21 days of each 28 day treatment **cycle**. You have up to 12 cycles unless your lymphoma stops responding or you develop troublesome side effects.

Zanubrutinib

Zanubrutinib blocks a protein called 'BTK' on the surface of B cells. This can make lymphoma cells die or stop them dividing.

You might be offered zanubrutinib if you have Waldenström's macroglobulinaemia (page 140) and you cannot have chemo-immunotherapy or if it has come back or not responded to treatment.

You take zanubrutinib as an oral tablet once or twice a day. You carry on taking it unless your lymphoma stops responding or you develop troublesome side effects.

Radiotherapy

Radiotherapy uses high-energy X-rays (a type of radiation) to destroy cancer cells. It stops them from dividing, so that they die off in time. Lymphoma cells are very responsive to radiotherapy.

The radiation is directed to precise areas of your body. This targets the lymphoma cells, while causing as little damage as possible to surrounding healthy cells.

Radiotherapy is a 'local' treatment, which means that it affects only the parts of your body being treated. It is therefore usually used to treat lymphoma that is only in one or two places in your body.

Radiotherapy might be used to treat early **stage** low-grade non-Hodgkin lymphoma that is only affecting one part of your body. In some cases, this can cure the lymphoma. Radiotherapy might also be used to treat advanced stage lymphoma if there are particular areas of lymphoma that are causing problems.

Having radiotherapy

You'll need to go to hospital for your radiotherapy treatment to be planned, and each time you have it. Not all hospitals have a radiotherapy department, so you might need to travel a bit further to one that does.



Photo credit: My Ocean Production/Shutterstock.com

Having radiotherapy

Your treatment is carefully planned by a radiotherapy team, led by a clinical oncologist (sometimes known as a radiation oncologist), who will work out:

- **exactly where the lymphoma is**, using a radiotherapy CT planning scan, so that they can direct radiotherapy to precisely this area
- **the total dose of radiotherapy** to give you
- **how many separate treatments (fractions)** you should have.

Your radiotherapy team only give radiation that is known to be within safe limits. They also plan your treatment to avoid damaging critical organs such as your brain or heart.

Your clinical team will explain the side effects you might experience during and shortly after your radiotherapy treatment, as well as possible **late effects** which might occur months to years after treatment.

To help make sure that radiotherapy goes to exactly the same place each time you have treatment, you might have some tiny permanent dot-like marks made to your skin, using a needle and ink. These are lined-up with the X-ray beams on the radiotherapy treatment machine to help make sure that the radiotherapy goes to exactly the right place.

If you are having radiotherapy to your head, neck, armpit or chest, you might instead have a plastic radiotherapy mask (sometimes called a 'shell') to wear each time you have treatment so that the radiotherapy goes to exactly the right place.

“ *I had to have a head and neck ‘shell’ or ‘mask’ made to ensure I received radiotherapy to exactly the same position each time. A mesh-like material was placed in warm water and then placed over my head, neck and shoulders – I could just about see through it. It was then massaged into me like quick-setting plaster. It’s semi-hard (pliable but retains its shape)*



and felt tight but I could breathe easily. I found that the best way to cope was to think about totally different things.

Julian, diagnosed with marginal zone lymphoma

Each radiotherapy session takes around 10 to 20 minutes. Most of this time is spent getting you into position – the radiotherapy treatment itself takes only a few minutes. Having radiotherapy doesn't hurt. During the treatment, the radiotherapy staff have to leave the room but they can see you and hear you at all times.

Typically, you have radiotherapy treatment Monday to Friday for up to 5 weeks. However, your schedule might differ from this as your treatment plan is designed specifically for you.

Radiotherapy treatment does not make you radioactive. People around you, including children, are not at any risk from being near to you after you've had treatment.

It can be helpful to take someone with you to the hospital for emotional support. They'll need to wait outside the treatment room to avoid unnecessary radiation.



Listen to our podcast where Consultant Clinical Oncologist, Professor George Mikhaeel, explains what radiotherapy is and when it is used in the treatment of lymphoma. You can hear it on our website, on Apple podcasts or on Spotify. Search 'radiotherapy podcast' at lymphoma-action.org.uk

High dose chemotherapy with stem cell transplant

Sometimes your lymphoma doctor may recommend stronger treatment, known as 'high dose chemotherapy'.

High dose therapy is often much stronger than other types of chemotherapy, and can cause long-term damage to the bone marrow and immune system. A **stem cell transplant** is required to help the bone marrow recover from the effects of high dose therapy.

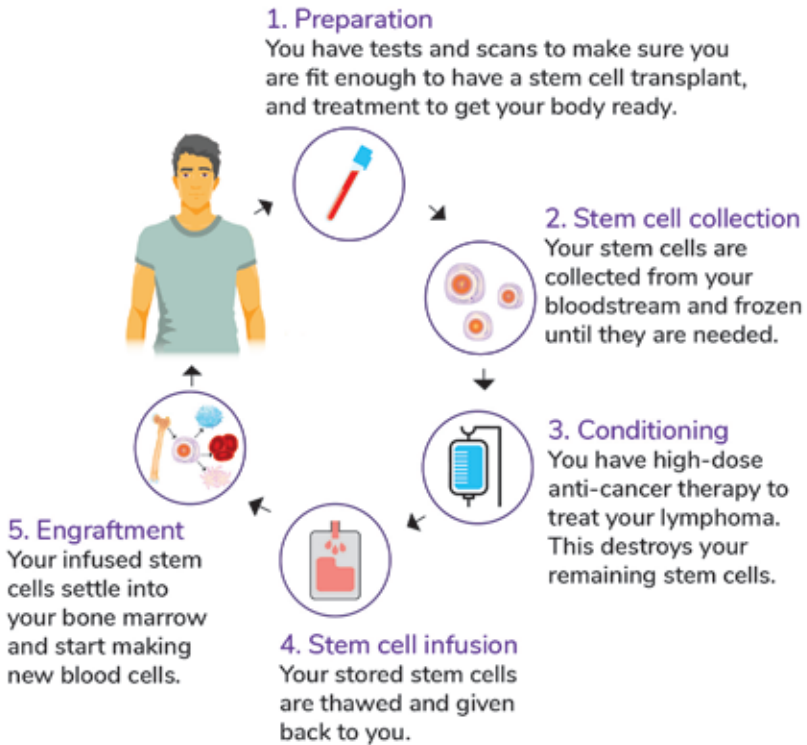
Stem cells are special cells in your **bone marrow** that make your red and white blood cells. A stem cell transplant is a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells.

Your clinical team might recommend high dose chemotherapy with a stem cell transplant after your initial treatment if you have a type of lymphoma that has a high risk of relapsing (for example, fast-growing mantle cell lymphoma; see page 134). They might also recommend high dose chemotherapy with a stem cell transplant if you have another type of low-grade non-Hodgkin lymphoma that has come back or not responded to initial treatment.

Having high dose chemotherapy with a stem cell transplant

This is a very intensive treatment option and you might have to stay in hospital for several weeks.

There are a number of steps involved in this treatment. You need tests beforehand to make sure you are fit enough to have one. If your clinical team thinks a stem cell transplant is suitable for you, they will talk to you in detail about it.



Autologous stem cell transplant process

If you are having a stem cell transplant using your own stem cells (**autologous** stem cell transplant), the cells are collected from your bloodstream before having high-dose chemotherapy. Occasionally, the stem cells come from a donor. This is called an **allogeneic** stem cell transplant.



We have separate information about stem cell transplants, including a book about autologous stem cell transplants. Visit lymphoma-action.org.uk/SCT

High-dose chemotherapy is given in hospital to make sure that your lymphoma is completely eliminated. This is often called ‘conditioning’.

On the day of your stem cell transplant, the stem cells are given back to you through your central line, just like a blood **transfusion**. Once the new stem cells are in your bloodstream they make their way to your bone marrow. They then settle into your bone marrow and start dividing to make new blood cells.

For 10 to 14 days after an autologous stem cell transplant, you have very low blood counts. Having a low **white blood cell** count, especially a type of blood cell called ‘**neutrophils**’ (neutropenia), puts you at very high risk of developing an infection. Your blood counts start to rise after 10 to 14 days but it can take several months for your **immune system** to recover.

While you are in hospital, your clinical team take precautions to reduce your risk of infection. They also keep close checks on you for any signs of infection.

Although there are things you can do to help lower your risk of infection, it's impossible to completely avoid all sources of infection. Tell a member of your clinical team as soon as you notice any signs or symptoms of infection (page 99) so that you have the best possible chance of effectively treating it.

CAR-T cell therapy

CAR-T cell therapy is a type of treatment that uses your own T cells or T **lymphocytes**. Your T cells are collected and genetically modified (changed) in the lab so they can recognise and kill lymphoma cells.

CAR-T cell therapy is used to treat some types of lymphoma that have come back (relapsed) or not responded (refractory) to treatment. You may be offered CAR-T cell therapy if you have mantle cell lymphoma that has come back after two previous therapies. CAR-T cell therapy is undergoing trials in other lymphoma types and may become more widely available in the future.

CAR-T cell therapy is a very intensive type of treatment and you have to be fit enough to have it.

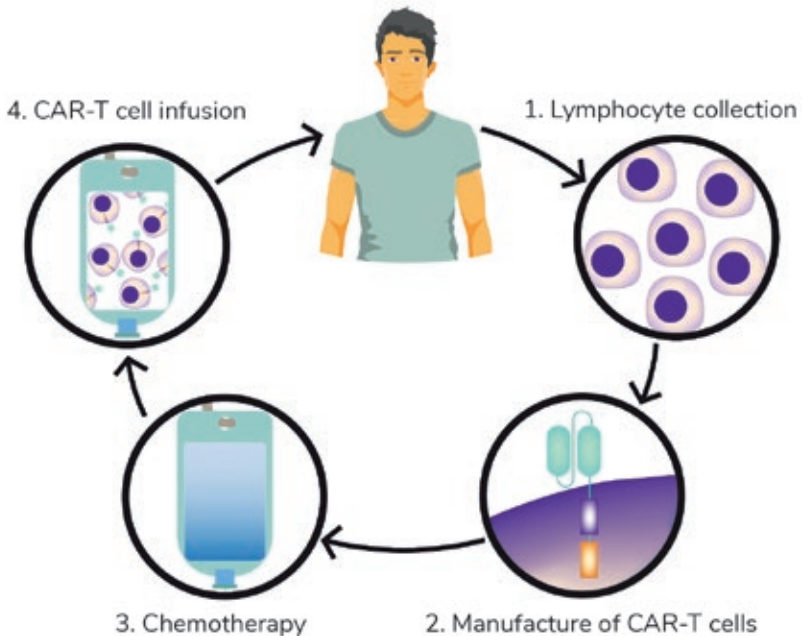
CAR-T cell treatments have to be made individually for each person. This can take several weeks. You are likely to have

other treatments to keep your lymphoma under control while the CAR-T cells are being made. This is called 'bridging therapy'.

Having CAR-T cell therapy

CAR-T cell therapy involves a number of different steps:

- collecting your T-cells from your blood
- making your CAR-T cells in a lab
- chemotherapy (known as 'lympho-depletion')
- having your CAR-T cells through a drip into a vein, or through a central line if you have one
- close monitoring and treatment of side-effects.



CAR-T cell treatment process

CAR-T cell therapy can cause serious side effects. It is only given in hospitals with the facilities and staff to treat side effects effectively. You have to stay in hospital to have the treatment, and you need to stay close to the hospital for another 2 weeks so you can be treated quickly if you develop any side effects.



For more information on CAR-T cell therapy, visit lymphoma-action.org.uk/CARTcells

Clinical trials

Clinical trials are medical research studies involving people. They are used to test new treatments or new ways of using existing treatments (for example, together with another treatment).

Your clinical team might ask you if you would like to take part in a clinical trial. Clinical trials are voluntary, it is completely up to you whether you do or not.

If your clinical team doesn't suggest a clinical trial and you are interested in taking part in one, ask if there is one that is suitable for you.

“ *The trial was randomised so I couldn't choose which treatment I had and neither could my doctor. I knew the options were the chemotherapy I would have had as a matter of course or a new immunotherapy drug. I was actually quite pleased when I heard I had been placed on the immunotherapy arm. I really feel part of something.*



Katie, diagnosed with
Waldenström's
macroglobulinaemia

Visit lymphoma-action.org.uk/TrialsLink for information about clinical trials, or to search for a trial that might be suitable for you.



Maintenance therapy

Maintenance therapy is a long-term treatment that is sometimes given after an initial course of treatment has put lymphoma into **remission** (disappearance or significant shrinkage of lymphoma). It aims to make your remission last as long as possible by ‘mopping up’ any lymphoma cells that might be left in your body.

You might be offered maintenance therapy if you have follicular lymphoma (page 133) or mantle cell lymphoma (page 134) that has responded well to a course of treatment.

Maintenance therapy usually involves having an injection of an **antibody therapy** (page 77) once every 2 to 3 months. If your lymphoma stays under control, you usually carry on having it for 2 to 3 years.

“ *I finished treatment in September 2021 and have started maintenance therapy, having an infusion of obinutuzumab every 8 weeks, which I am due to have for two years.*

Nicola, diagnosed with follicular lymphoma

Side effects of treatment

Treatment destroys lymphoma cells but it can also damage healthy cells, causing unwanted side effects.

Your clinical team can give you information about any side effects you might experience. They base this on lots of factors, including the type of treatment you have, how much of it, and how often, as well as 'individual factors', such as your age. However, different people can get different side effects, even if they're having the same treatment.

Usually, side effects are short-term and start to go away once you finish treatment. However, they can have a significant impact on your day-to-day life, including your emotional wellbeing.

Tell your clinical team about any side effects you have or if you feel unwell during your treatment. There are often things they can do to help.

Your clinical team can offer suggestions about how to cope with side effects and might also offer suitable prescriptions to help. In some cases, you might also be offered a referral to a specialist who can offer further support.

Some of the common side effects of treatment include:

- **Fatigue** – extreme tiredness that can be physical, mental or emotional. This can be worsened by the emotional impact of living with lymphoma.
- **Low blood counts and risk of infection** – treatment can have a short-term effect on the number of blood cells you have. This can lead to **anaemia**, **thrombocytopenia** and **neutropenia** (page 100).
- **‘Chemo brain’** – cancer-related cognitive impairment, which affects thinking processes such as memory and attention. Some people describe this as a ‘mental fog’. You might find it difficult to plan, keep up with a conversation or remember things.
- **Hair loss** – some people experience hair loss or thinning. This can happen to the hair on your head, as well as elsewhere on your body.
- **Sickness** – nausea (feeling sick) and vomiting (being sick). There are effective anti-sickness medicines (antiemetics) that can help.
- **Difficulty eating** – food might taste or smell different, you might get indigestion or heartburn or feel full very quickly.
- **Reduced fertility or early menopause** – your doctors should talk to you about whether your lymphoma treatment is likely to affect your fertility.
- **Nerve damage (peripheral neuropathy)** – damage to the nerves of the peripheral nervous system (network of nerves outside of the brain and spinal cord). It can cause symptoms such as increased or decreased sensitivity to touch and temperature, and numbness and tingling (pins and needles) in your hands and feet. Rarely, it can cause pain in your jaw.

- **Bowel problems** – diarrhoea, constipation and wind (flatulence).
- **Skin problems and irritations** – you might get dry, sore and itchy skin in some areas of your body, changes might also occur in your finger or toe nails.
- **Sore mouth (oral mucositis)** – which can cause symptoms such as pain when you swallow, mouth sores (ulcers), which can lead to infection, dry, sore mouth and lips.



You can find out more about the potential side effects of lymphoma treatments and how to cope with them at lymphoma-action.org.uk/SideEffects

Macmillan Cancer Support have information about wigs, hats, scalp care and more. Visit macmillan.org.uk/HairLoss

Low blood counts and risk of infection

Treatment for lymphoma can temporarily damage your bone marrow. Your bone marrow makes your body's blood cells.

It is common to have low blood counts during your treatment. Your clinical team regularly check your blood counts and make any adjustments to your treatment plan as necessary.

Neutropenia (low white blood cell count)

Having a low neutrophil count doesn't usually cause any symptoms but it means you have a higher risk of infection than normal. If you do get an infection, it can be serious, sometimes even life-threatening. **An infection in someone with neutropenia needs urgent treatment.** You usually have to stay in hospital for intravenous (IV) antibiotics and careful monitoring.

Possible symptoms and signs of infection include, but are not limited to:

- fever (temperature above 38°C/100.4°F)
- hypothermia (temperature below 35°C/95°F)
- shivering or rigors (even if you do not have a fever, which is more likely if you're taking steroid medication)
- chills and sweating
- feeling generally unwell, confused or disoriented
- blocked nose, earache, sore throat or mouth
- cough, yellow or green phlegm or snot (mucus), difficulty breathing
- redness and/or swelling of the skin, pain and redness around intravenous (IV) lines
- diarrhoea or vomiting
- a feeling of burning or stinging when you wee, or needing to wee more often than usual
- vaginal discharge or itching
- unusual and new stiffness of the neck with discomfort around bright lights
- new and increasing pain.

Contact your clinical team if you have any of these signs or symptoms, no matter how minor they might seem.

Anaemia (low red blood cell count)

If you have a low red blood cell count, you don't have enough haemoglobin (the cells that carry oxygen around your body). This is called **anaemia**. It might make you feel tired or short of breath. If your red blood cell count is very low, you might need treatment with a blood **transfusion** – a drip (infusion) of donated blood or blood products given into one of your veins.

Tell your doctor if you feel short of breath, unusually tired, dizzy or have new aches and pains, especially cramps in your legs when you walk or sleep. This could be a sign of anaemia that needs treatment.

Thrombocytopenia (low platelet count)

Thrombocytopenia is a shortage of platelets. You might bruise easily, bleed more or bleed for longer than usual if you hurt yourself if you are thrombocytopenic.

Thrombocytopenia often gets better on its own quite quickly. However, if your platelet count is very low, or you are at particular risk of bleeding, your clinical team might adjust your treatment or offer treatments to help your blood clot. In some cases, a transfusion of platelets is needed.

Contact your clinical team if you develop any of the following symptoms of thrombocytopenia:

- nosebleeds
- bleeding gums after brushing your teeth
- heavier or longer periods than is usual for you
- bleeding for longer than you'd expect after a cut or scratch
- bruising more easily than usual
- red or purple patches or spots called 'purpura' or 'petechiae' on your skin (often on your legs), your lips or in your mouth
- blood in your sick (vomit)
- blood in your wee
- blood in your poo (this might be obvious, bright red blood or it can make your poo black and sticky)
- persistent headache, blurred vision or a change in your level of consciousness.

If you have a low platelet count, take precautions to reduce your risk of bleeding. For example, avoid contact sports (such as rugby) and high-impact sports (such as football and martial arts). Wear gloves to protect yourself from injury while doing activities such as gardening, DIY and crafts such as sewing.

Tips to help lower your risk of infection

Keep good personal hygiene

- **Wash your hands before eating and after using the toilet.** Take antibacterial hand sanitiser gel or wipes with you if you are out and about.
- **Have a warm bath or shower each day.** Check with your clinical team for advice about bathing and showering if you have a chemotherapy central line (central venous catheter) in place.
- **Keep good dental hygiene.** Use a soft toothbrush and an alcohol-free antiseptic or antibacterial mouthwash.

Minimise contact with germs

- **Avoid places where you have a higher risk of catching an infection,** such as swimming pools, busy shops and public transport at peak times.
- **Avoid contact with people who are unwell,** for example with a cold, tummy bug or chickenpox.
- **Prepare food safely and don't eat anything that is past its sell-by-date** – use refrigerated food within 24 hours of opening. You can find out more about food safety on the World Health Organisation (WHO) website and the Food Standards Agency website.

- **Take care when handling pets** – avoid bites or scratches and wash your hands after any contact with an animal. If possible, ask someone else to deal with pet care jobs that involve animal poo, such as cleaning out litter trays.
- **Visit your dentist before you start treatment for lymphoma** – you might not be able to have any dental work done during or soon after treatment because of increased risk of infection.

Protect your skin

- **Protect yourself from cuts and scratches** by wearing gloves for gardening, wearing shoes when you are outside and avoiding walking barefoot indoors.
- **Keep your skin moisturised** with a body lotion or moisturiser if it becomes dry or cracked.
- **Allow spots and scabs to heal** without picking at them.

Treatments to help with symptoms and side effects

Some of your medicines might not be given to treat your lymphoma but to help improve your overall health and wellbeing. For example, you might be offered anti-sickness drugs (antiemetics), painkillers or antibiotics.

Steroids

Steroids are chemical messengers (hormones) that are made naturally in your body. If you have steroids as medication, the drugs copy the effects of these hormones. They are used to treat some types of lymphoma and to help control sickness (nausea and vomiting).

Side effects of steroids are usually short-term and improve once you stop taking them. They can include:

- muscle aches and weakness
- indigestion or heartburn
- increased risk of infection
- fluid retention
- changes in metabolism including higher blood sugar levels
- weakening of bones
- difficulty sleeping
- changes in mood.

Take any steroid medication you're given exactly as prescribed. Don't stop taking steroids suddenly without seeking medical advice, as withdrawal symptoms can be severe. Your clinical team can help you to stop taking steroids gradually.

Depending on your type of steroid medication and how long you are taking it for, you might be given a 'steroid treatment card' and a 'steroid emergency card'. If you are given either or both of these cards, carry them with you for all the time you are on steroids and for some time

after completing treatment with them. This is usually 12 months, but your clinical team will advise you based on your individual circumstances.

Growth factors

Growth factors are chemical messengers (hormones) that encourage cells to divide and develop.

Your body makes growth factors naturally. Growth factors can also be made in a laboratory and are sometimes used to boost your blood cell counts if they drop to low levels during chemotherapy.

The growth factor most commonly used is called 'granulocyte-colony stimulating factor' (G-CSF). You have G-CSF as an injection into the fatty tissue under your skin (subcutaneous injection). This is usually into your tummy, the top of your leg or the top of your arm.

You (or a friend or family member) will be taught how to give the injections so that you can have them safely at home. Other options can include having a community nurse visit you to give you the injections at home. Sometimes, it's possible to have them at your GP surgery.

The injections might sting a bit and cause side effects such as flu-like symptoms, back and pelvic pain, aches or headaches. For this reason they are often taken in the evening so that these side effects have worn off by the next morning.

Seek advice from your clinical team about how to cope with any side effects you experience – mild painkillers such as paracetamol often help, but check first that it's safe for you to take these.

Contact your doctor urgently if you develop the uncommon side effects of an itchy rash, swelling of your face, lips, tongue or throat, difficulty breathing or feeling faint after the injections.

Anti-sickness medication

There are many different types of anti-sickness medication (**antiemetics**) available, which work in different ways. Your clinical team will consider which type, how much and how frequently you might need to take antiemetics based on your risk of sickness. You might have to try a few to find out what works best for you.

Anti-infection prophylaxis

If you are at high risk of developing an infection, you might have treatment to help prevent you from getting infections. This is known as anti-infection prophylaxis.



Keeping active and maintaining a healthy diet can help during treatment. We have information about coping practically, physically and emotionally on our website and in our book *Living with and beyond lymphoma*.

Summary

- Chemotherapy is treatment that uses drugs to kill cancer cells. Most chemotherapy is given intravenously every few weeks.
- Targeted treatments attack proteins on cancer cells. There are different types of targeted treatments. Antibody therapy is often given in combination with chemotherapy.
- Radiotherapy is a localised treatment that uses high-energy X-rays to kill cancer cells.
- Different treatments cause different side effects. However, even people who have the same treatment might get different side effects.
- Treatment for lymphoma can temporarily affect your blood counts. This can lead to neutropenia (which can increase your risk of infection), anaemia (which can make you feel tired and breathless) and thrombocytopenia (which can make you bruise and bleed more easily).
- It's important to know the signs of infection (page 99) and who to contact if you notice any.
- As well as your treatment for lymphoma, you also have medicines to treat or prevent side effects or symptoms.



“

I had six sessions with a counsellor via BUPA following the end of treatment. I had been worried about the 'stigma' surrounding mental health and the fact that I felt I needed some counselling, but these sessions helped me massively. I would recommend counselling to anyone going through cancer treatment and people shouldn't hesitate to ask for help if they need it. I wish I had done that sooner.

Nicola, diagnosed with follicular lymphoma

After treatment

Feelings after treatment	110
Follow-up	113
Healthy living and day-to-day life	117
Late effects of treatment	120

Feelings after treatment

Finishing treatment for lymphoma can bring a range of emotions. Some of these are likely to be positive but others might be harder to cope with. You might feel differently at different times.

“ *We often hear from people when they finish their treatment. They might expect to feel relieved, elated, happy, but often, there is a mixture of different feelings they weren't expecting. We're here for anyone who would like to talk these through.*

Sharon, Lymphoma Action Information and Support Team

Some people feel anxious and low once their treatment finishes. You might start to really think about the reality of what you and those close to you have experienced, which can bring a new sense of shock, anger or sadness.

Many people miss the reassurance of frequent contact with their clinical team after treatment. You might worry about the future and any changes you need to make to your plans. It can be an added difficulty if friends and family expect you to feel happy – for some people, this leads to feeling irritated and isolated, as though those around them don't understand that this continues to be a challenging time.

Talking to someone about how you feel can help you to make sense of challenging feelings. You could speak to a family member or friend, or you might like to talk to someone who's been affected by lymphoma – our Helpline team might be able to link you with a peer-support Buddy who has personal experience of lymphoma (see page 150).

You could consider getting support from a counsellor. Speak to your GP or clinical nurse specialist if you're interested in counselling. They might be able to offer you a referral on the NHS. You can also search for a private therapist in your area using the British Association of Counsellors and Psychotherapists online tool: bacp.co.uk/search/Therapists



- Search ‘health and wellbeing’ on our website to find a range of resources to help with your physical and emotional wellbeing.
- We have information about recovery from treatment, including about adjusting to life after treatment. Search ‘recovery’ at lymphoma-action.org.uk
- You might also be interested in our tips to help you communicate with the people around you. Search ‘communicating’ on our website.
- Search ‘Live your Life’ on our website to find out about our self-management programme, designed for people who have finished treatment or are on active monitoring.
- We also have a list of useful organisations on our website, including those that can help with aspects of emotional wellbeing. Search ‘useful orgs’ at lymphoma-action.org.uk

If you’d like to talk about how you’re feeling, call our free Helpline on 0808 808 5555 (see page 150).

Follow-up

After finishing treatment for lymphoma, your clinical team are there to support you in your physical and emotional recovery.

End-of-treatment appointment

You have an end-of-treatment appointment with your clinical nurse specialist or another health professional.

- You'll be asked about your health and wellbeing, for example, about how you're feeling, any symptoms you have and how you're adjusting to life after treatment. To help guide the conversation, your clinical nurse specialist might use a questionnaire, which is sometimes called a holistic needs assessment (HNA).
- You might also be examined and have blood tests.
- You usually have a scan at the end of your treatment to check how well your lymphoma has responded. However, scans aren't routinely used as part of ongoing follow-up as there is no evidence to suggest that they change lymphoma treatment or outcomes. Doctors prefer to keep scans for when they're considered to be helpful, to help keep any radiation to a minimum.

Your end-of-treatment appointment is also a chance to ask any questions you might have about your lymphoma and the impact it has on your life.

Some people find it helps to write down any questions they have before their appointment. You could also note down the answers or key points of discussion during the appointment.

Together, you and your clinical team put together a care and support plan that is specific to your individual needs. This is known as personalised care and support. It includes needs that are physical, emotional, social or financial, for example, about day-to-day life, work, vaccinations and travel.

Our *Introduction to lymphoma* book includes suggested questions you might like to ask your clinical team, including about follow-up, and recovery after treatment, and a personalised care plan.

As well as the support your clinical team offer, there might also be a health and wellbeing event of interest to support you in your recovery. For example, we have a peer-led Live your Life self-management programme.

Follow-up appointments

Your follow-up appointments might be in person, over the phone or by video call. The aims are to check:

- your recovery from treatment
- for any signs that your lymphoma has come back (relapsed) – though, most of the time, these are noticed first by the person with lymphoma
- for any late effects (page 120).

You usually have follow-up appointments every few months for the first year. After this, appointments usually become less frequent. How long your follow-up continues depends on your symptoms and the treatment you've had.

If it is suitable for you, you might be offered a supported self-management system, although this isn't available at all hospitals. The idea is that you are supported to develop the skills, knowledge and confidence to book your own follow-up appointments, as-and-when you feel you need one.

Whichever way you are followed-up, you can contact your clinical team at any time. Don't wait until your next appointment is due if you are worried about your lymphoma.

At your follow-up appointments, you might see your consultant, clinical nurse specialist, or another member of your clinical team. They talk to you about how you're feeling and how you're adjusting to life after treatment. They might examine you and take some blood tests.

You might feel anxious before your follow-up appointments. They are an inevitable reminder of your lymphoma at a time when you are trying to move on. **Remember that if you have no new symptoms, it is unlikely your lymphoma has come back.**

Your GP should have a record of your diagnosis and all the treatment you've had. However, it's a good idea to remind them that you have had treatment for lymphoma. You should also tell any health professional who treats you in the future, including your dentist.

Healthy living and day-to-day life

Following a healthy lifestyle puts you in the best position to live well, with and beyond lymphoma. This includes:

- eating a healthy, balanced diet
- taking regular physical activity
- maintaining a healthy weight
- not smoking
- getting enough sleep
- managing stress
- protecting yourself from the sun
- keeping up-to-date with any vaccinations your clinical team recommend
- taking up any screening programme checks you're invited to.

Your clinical team can also tell you about any **late effects** to be aware of (page 120) and give you advice about other aspects of your life, such as safety precautions to take if you travel to another country.

We have more information about these lifestyle factors on our website and in our book *Living with and beyond lymphoma*.



Practicalities

You might need to make some short-term or longer-term changes in your day-to-day life. For example, with practicalities such as work, studying and social activities. Your clinical team should support you in finding ways to manage these aspects of your life.

Your employer must, by law, make any ‘reasonable adjustments’ that allow you to continue working during and after your treatment. Under the Equality Act 2010, this applies forever, not just while you are having treatment or for a limited time after finishing.

If you are a young person, you can find information about adjusting to life after treatment for lymphoma in our *Young person’s guide to lymphoma*.

“ *It's taken me quite a time to recover, and because the job I do is pretty physical, I want to avoid putting too much stress on my body for as long as I can. I have my own business and am fortunate that my two colleagues have been able to keep*



everything going while I've been away. I'm just planning to return to two days a week, albeit rather cautiously.

Cornita, diagnosed with low-grade non-Hodgkin lymphoma



Search 'day-to-day' on our website for more information about where to find support with practicalities.

When someone close to you has lymphoma

There is a range of possible sources of support available to people who are looking after a family member or friend who has lymphoma. For example, you might be entitled to financial support. If you are employed, you could also speak to your employer about making adjustments to your work and about taking time out, for example, to support the person you care for by going to medical appointments with them.

If someone close to you has lymphoma, we have a book for family and friends called *When someone close to you has lymphoma*. We also have information for you on our website – search ‘caring for someone who has lymphoma’ at lymphoma-action.org.uk

Late effects of treatment

Late effects are health problems that develop months or years after treatment for lymphoma. Most people with low-grade non-Hodgkin lymphoma have very few late effects. Your clinical team should talk to you about the possible late effects of your treatment before it starts.

While it’s not possible to say for certain whether you’ll develop late effects, your clinical team can give you an idea based on your specific lymphoma, the treatment you’ve had and individual risk factors, such as your age and lifestyle.

You can't always prevent late effects but noticing problems early gives you a better chance of treating or managing them effectively.



We outline some of the possible late effects of treatment for lymphoma below. You'll find more information on our website. Search 'late effects' at lymphoma-action.org.uk

“ *Understanding late effects is such an important part of rehabilitation after treatment. Knowing what organs might have been affected allows people to focus in on what areas are most important when planning life after treatment.*

Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology

Note that if you need to have a blood transfusion in the future, you may need blood that has been irradiated (treated with X-rays). This is to help prevent transfusion associated graft-versus-host disease (TA-GvHD), which is a rare but very serious complication.

Lung problems

Some treatments for lymphoma can cause scarring of your lungs (pulmonary fibrosis). This can happen with **radiotherapy** to the chest or very occasionally may be caused by drug treatment. If the damage is slight, you might not have any symptoms. If it is more severe, it can affect the type and amount of physical activity you're able to do. Your clinical team can give you advice about exercise that is suitable for you.

You are more likely to develop lung problems after lymphoma treatment if you smoke. If you smoke and would like free support to help you stop, talk to your GP or visit [nhs.uk/smokefree](https://www.nhs.uk/smokefree)

Heart problems

Radiotherapy to your chest and some **chemotherapy** drugs can damage your heart. This includes doxorubicin, a component of CHOP.

Heart problems generally don't start until at least 10 years after treatment, but they can develop sooner. Your risk of developing heart problems stays higher than usual for several decades after your treatment.

You can lower your risk of developing heart problems by not smoking, maintaining a healthy weight, eating well and staying active. You should also have your blood pressure, blood sugar level and cholesterol level checked regularly. Ask your GP surgery for information about how to book these.

Visit [bhf.org.uk](https://www.bhf.org.uk) for information about heart problems and advice on keeping your heart healthy.

Other cancers

Treatment for low-grade non-Hodgkin lymphoma can increase your risk of developing another cancer in the future. However, this risk is small.

Most people who have been treated for lymphoma never develop another cancer.

The type of cancer you might be at risk of developing depends on the treatment and dose you had, how old you were when you were treated and how old you are now.

Ask your clinical team what cancers you might be at a higher risk of developing. Make sure you know the symptoms of these cancers. Cancer is usually more treatable if it is diagnosed early.

Following a healthy lifestyle (page 117) can help to reduce your risk of health problems in general, including other cancers. Staying safe in the sun is important to reduce the risk of skin cancers.



Find information online about screening programmes available in your region of the UK. Go to lymphoma-action.org.uk and search 'useful orgs'.

Hormone problems

Treatment for lymphoma can affect the production of chemical messengers (hormones) in your body. This can lead to:

- underactive thyroid (hypothyroidism)
- reduced fertility
- early menopause.

Talk to your clinical team or GP if you have any concerns as specialist help may be available.

Underactive thyroid

If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid (hypothyroidism). This is where your thyroid gland makes less of the hormone thyroxine than it should. Thyroxine controls how your body uses energy. If you have too little of it, you might feel tired, sensitive to the cold and constipated. You might also gain weight easily.

The risk of developing hypothyroidism is highest within the first 5 years of having treatment. It stays increased after this time compared to if you had not ever had treatment for lymphoma.

Hypothyroidism is diagnosed by a blood test and is easily treated with thyroxine tablets. You might be offered regular blood tests to keep checks on your thyroid functioning.

You can find out more about hypothyroidism on the British Thyroid Foundation's website: btf-thyroid.org

Reduced fertility

Some treatments for lymphoma can affect women's ovaries and men's testicles, leading to reduced fertility. This can happen with radiotherapy given to your tummy (abdomen) area or to the area below your belly button (pelvis). It can also happen with chemotherapy. Less is known about the effects of newer, targeted treatments.



We have separate information about reduced fertility on our website. This includes information about fertility preservation options for men and women. Search 'fertility' at lymphoma-action.org.uk

Early menopause

Cancer treatments work by killing cells that are dividing quickly. As well as cancer cells, they can also affect some healthy cells, including those in the ovaries that are involved in the development of eggs. When the ovaries stop releasing eggs, levels of the hormones oestrogen and progesterone drop. This causes periods to stop and can cause an early menopause.



We have separate information about early menopause on our website, including symptoms, tips on coping and frequently asked questions. Search 'menopause' at lymphoma-action.org.uk

Less common late effects

There are some other, less common late effects of lymphoma treatment. These might include eye problems such as dryness and cataracts. **Radiotherapy** can increase your risk of tooth decay or brittle bones, depending on the area of the body treated.

Ask your clinical team about any specific late effects you should be aware of.

There is support available to help you live well, with and beyond lymphoma. This includes support needs that are physical, emotional, social, financial and practical. Speak to your clinical team for advice. We are also here to support you – see page 150 to find out how.

Summary

- Many people feel a wide range of emotions when they finish treatment. There is support available to help you through this time.
- After treatment, you have follow-up appointments to check your recovery and to help you manage any side effects or late effects of treatment. It also gives you a chance to talk to your clinical team about questions or concerns you might have.
- A healthy lifestyle helps in your recovery and to live well, with and beyond lymphoma.
- After treatment, you might need to make some short or longer-term adjustments to your day-to-day life. This might include your work or studies.
- Late effects are health problems that can develop months or years after treatment. Your clinical team should talk to you before you begin treatment about any you might experience.



Notes



“ *I had heard of lymphoma as one of my friends in the UK had been treated for it three years beforehand. But a bit of investigation on the Lymphoma Action website quickly made me realise that lymphoma isn't just one cancer; there are many different types.*

Stephen, diagnosed with mantle cell lymphoma

Types of low-grade non-Hodgkin lymphoma

Follicular lymphoma	133
Mantle cell lymphoma	134
Marginal zone lymphomas	135
MALT lymphoma	135
Nodal marginal zone lymphoma	138
Splenic marginal zone lymphoma	139
Waldenström's macroglobulinaemia	140

Low-grade non-Hodgkin lymphoma

There are many different types of **low-grade** non-Hodgkin lymphoma. In this chapter, we cover some of the more common types, including any specific symptoms and treatments.

You might want to read only the section on your own type of lymphoma. If you are not sure exactly what kind of lymphoma you have, ask your doctor or nurse.

We have not included every type of low-grade non-Hodgkin lymphoma. Some types have more than one name, so check with your clinical team in case we have listed your type under another name. If not, they might be able to tell you if we have included a lymphoma similar to yours, or advise you on where you can get more information.



- We have more information on most of the different types of low-grade non-Hodgkin lymphoma. View or download our information sheets at lymphoma-action.org.uk/information or call 0808 808 5555 to request a copy.
- We also produce separate information on skin lymphomas, which are often treated differently from other types of lymphoma. Visit lymphoma-action.org.uk/SkinLymphoma

Follicular lymphoma

Follicular lymphoma is the most common type of low-grade non-Hodgkin lymphoma. It is called 'follicular' because the abnormal cells usually develop in clumps called 'follicles'. It can develop at any age, but it is more common in people over 60.

Symptoms: Symptoms of follicular lymphoma usually develop gradually. The most common symptom is a lump or several lumps, often in the neck, armpit or groin. Most people have no other symptoms.

Treatment: If your lymphoma is growing slowly and is not causing problems, you are likely to have active monitoring (watch and wait; page 57) or a course of rituximab (page 78). Most people who have symptoms and need treatment have **chemo-immunotherapy** (page 78). You might have **radiotherapy** (page 82) if your lymphoma is only affecting one part of your body. After treatment, most people have **maintenance therapy** (page 94).

If follicular lymphoma **relapses**, treatment options include more **chemo-immunotherapy** (page 78) or lenalidomide plus rituximab (page 81). You might have maintenance therapy if you have not had it previously. If your lymphoma relapses very quickly, your clinical team might recommend a **stem cell transplant** (page 88).

Mantle cell lymphoma

Mantle cell lymphoma develops from B cells. It is called 'mantle cell' because the cells come from a region of the **lymph nodes** called the 'mantle zone'. Although doctors consider it to be a type of low-grade lymphoma, it can also grow quickly.

It develops most often in people in their 60s. It is more common in men than women.

Symptoms: Mantle cell lymphoma usually causes swollen lymph nodes but it has often spread to other areas of the body by the time it is diagnosed. It can affect the **bone marrow**, bloodstream, bowel, **spleen** or tonsils.

Treatment: If your lymphoma is growing slowly and is not causing problems, you might be put on active monitoring (watch and wait; page 57). Otherwise, if you are fit enough, you are likely to have a **chemo-immunotherapy** regimen that includes a drug called cytarabine, followed by an **autologous stem cell transplant** (page 88) to make your **remission** last longer. After treatment, most people have rituximab **maintenance therapy** (page 94).

If a stem cell transplant is not suitable for you, you might have a different chemo-immunotherapy regimen such as R-CHOP or bendamustine and rituximab. People with lymphoma in just one area of the body might have **radiotherapy** (page 82).

If your mantle cell lymphoma **relapses**, you are likely to be offered ibrutinib (page 80) or more chemo-immunotherapy. Some people have an **allogeneic** stem cell transplant (page 87) if they are fit enough, although this is uncommon. If mantle cell lymphoma relapses again after treatment with ibrutinib you may be offered CAR-T cell therapy (page 90).

Marginal zone lymphomas

Marginal zone lymphomas develop from B cells. They are called 'marginal zone' because they develop in a region at the edge of **lymphoid tissues** (collections of **lymphocytes**) known as the marginal zone.

There are three types of marginal zone lymphoma:

- MALT lymphoma, which develops in lymphoid tissues outside **lymph nodes**
- nodal marginal zone lymphoma, which develops in lymph nodes
- splenic marginal zone lymphoma, which develops in the **spleen**.

MALT lymphoma

MALT lymphoma is also known as 'extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue'. Mucosa-associated lymphoid tissue (MALT) refers to collections of lymphocytes in your mucosa (the moist, protective layer of cells that lines many parts of your body, such as your mouth, gut, airways and some internal organs).

MALT lymphomas are normally divided into gastric (stomach) MALT lymphoma and non-gastric MALT lymphoma.

Gastric MALT lymphoma

Gastric MALT lymphoma develops in the stomach. It is strongly linked to infection with bacteria called *Helicobacter pylori* (*H. pylori*). This is a very common infection. It doesn't usually cause serious problems. Most people with *H. pylori* infection do **not** develop lymphoma.

Symptoms: Persistent indigestion is usually the only symptom of MALT lymphoma. Some people might have tummy pain, sickness, weight loss or anaemia. Some people don't have any symptoms at all.

Treatment: Clearing the *H. pylori* infection with antibiotics and acid-reducing medication also clears the lymphoma in most people. You might need several courses of treatment to clear the infection. If this does not get rid of your lymphoma, you might need **radiotherapy** (page 82), or **chemo-immunotherapy** (page 78). If your lymphoma is not causing problems, you might have a period of active monitoring (page 57).

If your lymphoma **relapses**, the same treatments are often successful again. You might be asked if you'd like to take part in a clinical trial (page 92).

Non-gastric MALT lymphoma

Non-gastric MALT lymphoma develops in areas where MALT tissue has formed in response to inflammation. It is linked to infections with certain bacteria or particular autoimmune conditions (when your **immune system** mistakenly attacks your own body).

Symptoms: Most people have no symptoms at all and the lymphoma is found during tests to investigate something else. If symptoms develop, they depend on where the lymphoma is growing. It most commonly affects the spit (salivary) glands, **thyroid**, lungs, skin, gut (bowel) or tissues around the eye.

Treatment: If your lymphoma is not causing problems, you might have a period of active monitoring (watch and wait; page 57). If it is linked to an infection, clearing the infection with antibiotics might also clear the lymphoma. Some people with non-gastric MALT lymphoma need **radiotherapy** (page 82) or **chemo-immunotherapy** (page 78).

If your lymphoma **relapses**, you might be asked if you'd like to take part in a clinical trial (page 92) or you might have more chemo-immunotherapy.

Nodal marginal zone lymphoma

Nodal marginal zone lymphoma develops in **lymph nodes**. It can occur at any age but is most common in people over 50. It is sometimes linked to hepatitis C virus infection and some autoimmune conditions. However, the vast majority of people who have had hepatitis C or autoimmune conditions do **not** go on to develop lymphoma.

Symptoms: Most people have swollen lymph nodes, typically in the neck but they can develop in other places. This is usually the only symptom. Some people feel very tired and have **B symptoms**.

Treatment: If your lymphoma is not causing problems, you are likely to have active monitoring (watch and wait; page 57). If you have hepatitis C virus infection, clearing the infection with antiviral medication might clear the lymphoma. If you need other treatment, you might have **radiotherapy** (page 82) if your lymphoma is only affecting one part of your body. Most people who need treatment have **chemo-immunotherapy** (page 78).

If your lymphoma **relapses**, you might be asked if you'd like to take part in a clinical trial (page 92) or you might have more **chemo-immunotherapy**. Rarely, if your lymphoma relapses very quickly, your clinical team might recommend a **stem cell transplant** (page 87).

Splenic marginal zone lymphoma

Splenic marginal zone lymphoma is a rare type of lymphoma that develops in your **spleen**. It can affect people of any age but is most common in people in their 60s. Some cases are linked to hepatitis C infection and some autoimmune conditions. However, the vast majority of people who have had hepatitis C or autoimmune conditions do **not** go on to develop lymphoma.

Symptoms: Most people have an enlarged spleen, which might cause discomfort in your tummy or chest, or a feeling of being full very quickly after eating. Some people have low blood counts or symptoms caused by abnormal antibodies, such as poor circulation or a rash in cold weather.

Treatment: If your lymphoma is not causing problems, you are likely to have active monitoring (watch and wait; page 57). If you have hepatitis C virus infection, clearing the infection with antiviral medication might clear the lymphoma. If you need other treatment, you are likely to have **antibody therapy** (page 77) on its own or combined with **chemotherapy** (page 68). Radiotherapy may also be a treatment option, especially if your spleen remains enlarged at the end of treatment. Very rarely, if your spleen is very large, you might need an operation to remove it (a splenectomy).

If your lymphoma **relapses**, you might be invited to take part in a clinical trial (page 92) or you might have more **chemo-immunotherapy**.

Waldenström's macroglobulinaemia (lymphoplasmacytic lymphoma)

Lymphoplasmacytic lymphoma (LPL) is a rare lymphoma that develops from B cells that are actively making antibodies. It is most common in people over 65. It affects more men than women. Most cases of LPL are a type called Waldenström's macroglobulinaemia (WM).

Symptoms: The symptoms of WM are very variable. You might have low blood counts or symptoms caused by abnormal antibodies, which can make your blood too thick. This can cause nosebleeds, vision changes, dizziness or headaches, drowsiness, poor concentration, confusion and shortness of breath. Swollen **lymph nodes** and **B symptoms** are less common than with other types of lymphoma.

Treatment: If your lymphoma is not causing problems, you are likely to have active monitoring (page 57). If you need treatment, you are likely to have **chemo-immunotherapy** (page 78). If you have high levels of abnormal antibodies which make your blood too thick, you might need to have it thinned by a procedure called 'plasmapheresis' (plasma exchange).

If your lymphoma relapses, you might have a further period of active monitoring (page 57), more chemo-immunotherapy (page 78) or zanubrutinib (page 81). Rarely, if WM relapses very quickly, your clinical team might recommend a **stem cell transplant** (page 87).



Notes

Glossary

- Active monitoring** a period when you have regular check-ups to monitor how your lymphoma is affecting you before you start treatment; also called ‘watch and wait’
- Allogeneic** tissues or cells that come from a donor, rather than from you
- Anaemia** low red blood cell count, which means you don’t have enough haemoglobin (the protein that carries oxygen around your body)
- Anaesthetic** drugs given to make a part of the body numb (local anaesthetic) or put your whole body into a sleep-like state (general anaesthetic)
- Antibodies** proteins made by white blood cells that stick to proteins on things that don’t belong in your body, such as viruses, bacteria and some cancer cells
- Antibody therapy** treatment that uses antibodies made in a laboratory to target cancer cells

Antiemetic	anti-sickness medicine that can help to reduce nausea (feeling sick) and vomiting (being sick)
Autologous	the use of your own tissues or cells, rather than a donor's
B symptoms	a set of symptoms: fever, drenching sweats and unexplained weight loss
Biopsy	a biopsy looks at a sample of cells under a microscope to check for lymphoma cells
Bone marrow	the spongy material at the centre of larger bones
Bulky disease	swollen lymph nodes that can form large lumps
CAR-T cell therapy	treatment that uses genetically modified versions of your own T cells to recognise and kill lymphoma cells
Central nervous system (CNS)	your brain and spinal cord
Chemo-immunotherapy	chemotherapy combined with antibody therapy

Chemotherapy	treatment with anti-cancer drugs
Chemotherapy regimen	a chemotherapy treatment plan
Contrast agent	a type of dye given as a drink or injection to help show up internal structures clearly on scan images
Cycle	a round of treatment followed by a rest period to give you time to recover before the next round of treatment
Extranodal	outside the lymph nodes
High-grade	a type of lymphoma that can progress quickly; also called ‘fast-growing’ or ‘aggressive’
HIV	human immunodeficiency virus: the virus that causes AIDS
Immune system	the system in your body that fights off and prevents infection
Immunotherapy	treatment that helps your immune system recognise and destroy cancer cells
Late effects	health problems due to treatment that develop months or years after treatment

Low-grade	a type of lymphoma that progresses slowly; also called 'slow-growing' or 'indolent'
Lymphatic system	part of your immune system, the lymphatic system is a network of tubes, nodes and organs that filters out germs and toxins, helps destroy cells that are old or damaged and drains waste fluids from your tissues
Lymph nodes	small, oval glands that are spread throughout your lymphatic system; they help your body fight infections and drain away waste fluids from tissues
Lymphocytes	specialised white blood cells that are part of your immune system
Lymphoid tissue	a collection of lymphocytes
Maintenance therapy	treatment to keep lymphoma in remission for as long as possible
MRI	magnetic resonance imaging: a scan that uses magnetic waves to take pictures of the inside of your body

Multidisciplinary team (MDT)	a team made up of different professionals, sometimes from more than one hospital, that plans your treatment
Neutropenia	shortage of neutrophils in the blood
Neutrophils	a type of white blood cell that is important in fighting infections
Peripheral neuropathy	damage to the nerves of your peripheral nervous system, which carries signals between different parts of your body
PET/CT scan	a test that combines a PET scan and a CT scan
Platelets	small cells in your blood that help your blood to clot when you cut yourself
Proteins	proteins have different roles, including controlling how our cells work and helping to fight infections
Radiotherapy	treatment that uses high-energy X-rays (a type of radiation) to destroy cancer cells
Red blood cell	carry oxygen around your body

Refractory lymphoma	lymphoma that doesn't respond to treatment
Relapsed lymphoma	lymphoma that comes back after treatment
Remission	disappearance or significant shrinkage of lymphoma
Spleen	an organ that filters blood
Stage	a measure of how much of your body is affected by lymphoma
Stem cells	undeveloped cells that can mature into many different cell types
Stem cell transplant	a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells
Steroid	a medicine with anti-cancer effects that also affects your body's response to infection and injuries
Targeted treatment	drugs that attack particular proteins on lymphoma cells
Thrombocytopenia	shortage of platelets in the blood

Thymus	a small gland behind your breastbone where some of your immune cells develop
Thyroid	a gland at the front of your neck that produces a hormone called thyroxine, which controls how fast the cells in your body work
Transfusion	having blood or blood products given to you through a drip into a vein
Tumour lysis syndrome	rapid breakdown of tumour cells that releases chemicals that can damage your kidneys and heart
Ultrasound scan	use high-energy soundwaves to take pictures of the inside your body
White blood cell	a cell that helps your body fight infections; there are different types, including lymphocytes and neutrophils

Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites.

British Association for Counselling and Psychotherapy provides a list of accredited counsellors in your area.

Cancer Research UK offers information on all types of cancer, a searchable database of clinical trials and a helpline staffed by nurses: 0808 800 4040.

Carers UK offers advice, information and support for carers.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.

Maggie's provides practical, emotional and social support to people with cancer and their family and friends.

Young Lives vs Cancer provides emotional and practical support for young people with cancer and their families.

Visit [lymphoma-action.org.uk/Useful-Organisations](https://www.lymphoma-action.org.uk/Useful-Organisations) for a list of more organisations you might find helpful.



Information and support

If you or someone you love is affected by lymphoma, we're here to support you.



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website.



Find an **Online Support Meeting** at lymphoma-action.org.uk/OSM



Join our **Closed Facebook Group** at facebook.com/groups/LymphomaActionSupportUK



Our **Buddy Service** can connect you with someone in a similar situation to you. Call our Helpline for details.



Visit lymphoma-action.org.uk/TrialsLink to search for clinical trials that might be suitable for you.

See our website for full details of our services. For our latest news and updates, follow us on social media:



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lymphoma_action

If you're interested in finding out more about any of the topics covered in this book, we have lots more information on our website.

We also produce a number of books, which are available free of charge, including:

- *Introduction to lymphoma*
- *Active monitoring (watch and wait) for lymphoma*
- *Living with and beyond lymphoma*
- *Autologous stem cell transplant*
- *When someone close to you has lymphoma*
- *Young person's guide to lymphoma*
- A series of Easy Read books.

Find our full range of books and information at lymphoma-action.org.uk/Books or call us on 0808 808 5555.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo



More information

How you can help us

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.

References

The full list of references for this book is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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This book outlines what low-grade non-Hodgkin lymphoma is, possible treatment options, and what to expect after treatment.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years.

We're here for you.



Freephone helpline **0808 808 5555**
(Mon to Fri, 10am to 3pm)



information@lymphoma-action.org.uk



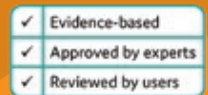
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